

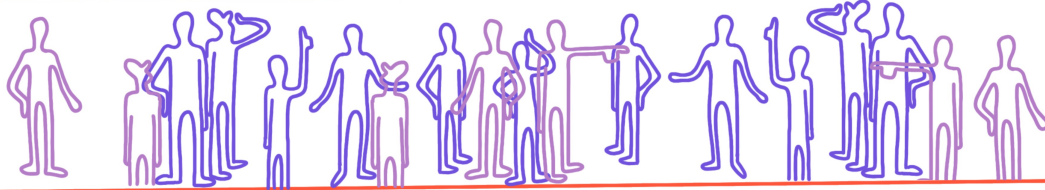
Global AIDS Strategy Development Process:

Synthesis of perspectives from a range of stakeholder interviews

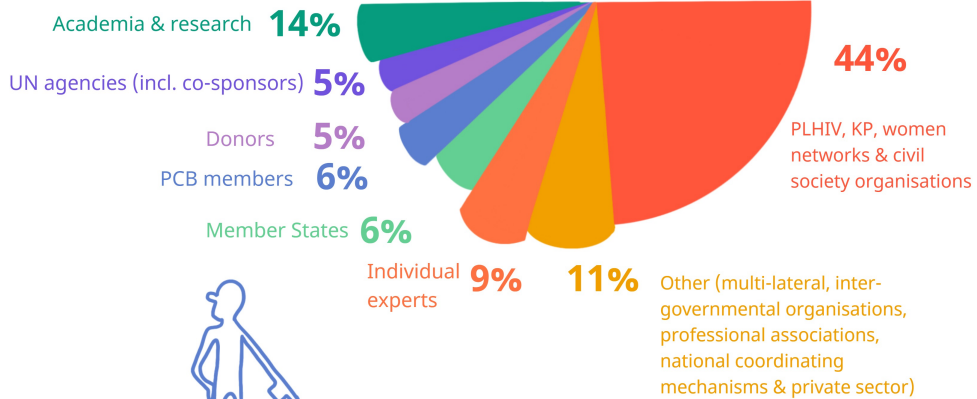
REPORT FOR THE MULTI-STAKEHOLDER CONSULTATION: 16 SEPTEMBER 2020

8 September 2020

DIALOGUE SYNTHESIS REPORT HIGHLIGHTS



65 INTERVIEWS



In theory the current strategy is good, implementation has been the challenge.

AREAS OF ALIGNMENT

- Take existing and emerging realities into account.
- Address structural drivers of inequality.
- Focus on both biomedical advances and human rights.
- Focus PLHIV and community-led responses.
- Collaborate and partner.
- The response must be granular and context specific.
- Mobilise exceptional political leadership.
- Properly finance the AIDS response.

AREAS OF DIVERGENCE

- Perspectives on the usefulness and appropriateness of the various goals, visions and targets.

- How broad or narrow should the next strategy be?

- Is UNAIDS fit for purpose?

CONCLUDING REFLECTIONS

Provide potential starting points for conversations in the first internal workshop on 20 and 21 August 2020, and the multi-stakeholder consultation on 16 September 2020.

TABLE OF CONTENTS

INTRODUCTION	1
1. CONTEXT	1
2. A NON-CONVENTIONAL APPROACH	2
3. METHODOLOGY	2
4. ADDRESSING UNAIDS AS AN ENTITY IN AN UNAIDS-LED GLOBAL AIDS STRATEGY PROCESS	3
5. THE PURPOSE OF THIS REPORT	3
6. HOW TO READ THIS REPORT	3
7. REPORT STRUCTURE	4
HOPES AND EXPECTATION FOR THE STRATEGY PROCESS	5
1. OVERVIEW	5
2. WHAT WAS ACTUALLY SAID	5
PERSPECTIVES ON THE CURRENT UNAIDS STRATEGY	8
1. OVERARCHING PERSPECTIVES	8
2. PERSPECTIVES ON PREVENTION	10
3. PERSPECTIVES ON TREATMENT	16
4. PERCEPTIONS ON STIGMA AND DISCRIMINATION	22
AREAS OF ALIGNMENT	31
1. TAKE EXISTING AND EMERGING REALITIES INTO ACCOUNT	32
2. ADDRESS STRUCTURAL DRIVERS OF INEQUALITY	36
3. FOCUS ON BOTH BIOMEDICAL ADVANCES AND HUMAN RIGHTS	41
4. FOCUS ON PEOPLE LIVING WITH HIV AND COMMUNITY-LED RESPONSES	43
5. COLLABORATE AND PARTNER	53
6. THE RESPONSE MUST BE GRANULAR AND CONTEXT SPECIFIC	57
7. MOBILISE EXCEPTIONAL POLITICAL LEADERSHIP	62
8. THE AIDS RESPONSE NEEDS TO BE PROPERLY FINANCED	66
AREAS OF DIVERGENCE	72
1. VISION, GOALS AND TARGETS	72
2. HOW BROAD OR NARROW SHOULD THE NEXT STRATEGY BE?	80
3. IS UNAIDS FIT FOR PURPOSE?	86
A FEW CONCLUDING REFLECTIONS	94
APPENDICES	96

Introduction

1. Context

UNAIDS is currently undertaking a multi-stakeholder participatory process to guide the process of developing the next UNAIDS global AIDS strategy.

This strategy process consists of two related phases, namely **Strategy Review (Phase one)** and **Strategy Development (Phase two)**. These two phases form part of a single integrated and coherent process, with the intention of developing a visionary, ambitious and evidence-based strategy for UNAIDS that will guide the global AIDS response. Phase One draws to a close in September at the Intersessional UNAIDS Programme Coordinating Board (PCB) meeting.



Figure 1: Overview of key activities and timelines that support the development of the next UNAIDS strategy

One of the main outcomes of Phase 1 Strategy Review is to provide the UNAIDS Programme Coordinating Board (PCB) with evidence regarding the overall direction of the next UNAIDS strategy. To this end, this Phase includes a number of quantitative and qualitative inputs, of which this dialogue interview synthesis is one. Other sources of data included a public online survey, focus groups and a strategy evidence review. This interview synthesis report should therefore be read alongside the following documents:

- UNAIDS strategy evidence review,
- Global strategy survey results, and
- Synthesised focus groups outputs.

These documents are key inputs for the first of three participatory workshops and one multi-stakeholder consultation scheduled for the Strategy Development Phase (Phase 2) of the process. This document should be viewed as an advanced draft for the workshop participants of the participatory workshops. This report will be finalised for public release prior to the multi-stakeholder consultation.

2. A non-conventional approach

To address the current and future challenges that stand in the way of effectively addressing the AIDS epidemic, requires all actors directly and indirectly affected by or with a stake in the issue to work together. UNAIDS thus committed to an inclusive, participatory, interactive, multi-sectorial and multi-level approach to this global strategy process and appointed Reos Partners to support this process.

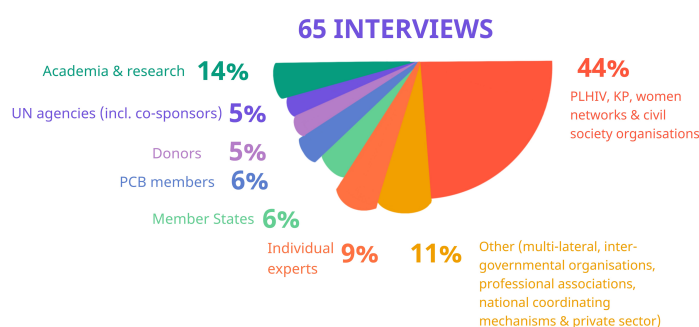
Reos Partners brings over 20 years of experience in putting collaboration at the centre of problem solving to drive impact on complex challenges. They design, facilitate, and guide (in person and / or distributed virtual) processes that enable teams of stakeholders—even those who don't understand or agree with or trust one another—to make progress on their toughest challenges. Their approach is systemic, experimental and collaborative. Central to their experience and expertise is bringing unlikely allies”, adversaries, and at times even enemies, together.

Dialogue interviews are one of these non-conventional approaches. Dialogue interviews are not simply diagnostic or data-collecting activities. They are tools that help participants shift from a reactive stand point to a reflective one and are used as a starting point when a 'business-as-usual' approach no longer influences complex challenges sufficiently. Dialogue interviews are built around well-crafted, open questions, posed by skilled interviewers, where participants are encouraged to reflect freely, thereby creating the conditions for them to more deeply consider their particular challenge and what opportunities might exist for a different approach.

The synthesis of these interviews is not meant to be an exhaustive or representative assessment of all perspectives. It is also not meant as a set of definitive facts or “truths” about the HIV/AIDS system, but rather a composite of at times, contradictory views— that collectively show up the complexity of the challenge and potential leverage points for change – by those immersed in different parts of the system. Instead it aims to capture the breadth of perspectives and positions that exist in the system, and in so doing builds trust, including by those who usually feel their views or perspectives are negated or silenced in the process. The ultimate intention of this synthesis of views is that it stimulates reflective, honest and strategic conversations of the past, the present and future, in a way that elicits insights that will inform a visionary, ambitious and actionable global AIDS strategy for the next five years.

3. Methodology

For the purposes of the UNAIDS strategy review, a total of 65 one-on-one semi-structured dialogue interviews were conducted by Reos Partners with more than 70 people, that collectively comprise a broad scope of stakeholders across the HIV/AIDS system. In line with the aspirational targets of placing PLHIV, KP, women and youth networks and civil society organisations at the centre of the process, the interviews gave preference to these groups while also eliciting views from a range of other stakeholders external to the UNAIDS Secretariat.



See Appendix A for full list of interview respondents. A list of guiding interview questions are provided in Appendix B. These open-ended questions were collaboratively agreed upon by the UNAIDS Strategy Development Team (SDT) and Reos Partners, with input from co-sponsors.

The interviews were recorded, summarised by interviewers using a pre-defined template and transcribed. The summaries and transcripts were analysed individually by Reos Partners using a qualitative data analysis tool called Dovetail. The primary question and sub-questions (See Appendix C) the Strategy Review Process aimed to address provided the basis for the analysis process. Tags (or keywords) were developed, refined, clustered in an iterative process that included regular engagement with the Reos Partners interview team and members of the UNAIDS Strategy Development Team, to validate emerging themes and to agree on the structure of the report. While there are elements on qualitative research methods that have been used, this was not intended to be nor does it purport to be a robust qualitative research report.

4. Addressing UNAIDS as an entity in an UNAIDS-led global aids strategy process

The primary focus of these stakeholder interviews were on the global AIDS response, not on the UNAIDS Joint Programme. However, given that UNAIDS was mandated by its Programme Coordinating Board (PCB) to conduct the Strategy Review process, it was inevitable that some interviewees spoke at length about the UNAIDS Secretariat and UNAIDS Joint Programme. This feedback forms part of what the “system is saying”, and is included as appropriate. At the same time, UNAIDS as an organisation is not at the centre of this strategy review process. This is consistent with the design and what emerged from the interviews.

5. The purpose of this report

The primary purpose of this dialogue synthesis report is to provide a snapshot of how a diversity of actors from across the HIV response system, in particular PLHIV and civil society organisations view the past, the present and the future of HIV/AIDS. As one of many inputs, this document provides a shared starting point for a series of conversations that will be undertaken in the coming weeks. As the reader, it is important to understand that this is a significant but perhaps messy and partial reflection on the global AIDS response. It is one of many important inputs. Therefore, its aim is not to drive towards definitive answers or conclusions, but to act as a prompt for further reflection and dialogue on what these diverse positions and perspectives might mean for the global HIV response. It serves to highlight or spark connections, possibilities and potential obstacles to progress.

6. How to read this report

The opinions gathered through the interviews have been captured as unattributed quotes and organised around a framework that emerged through the analysis process. The bulk of the synthesis report comprises these quotes, with minimal summarising text (in bold), so that each voice or quote can speak for itself. The quotes included are not exhaustive but have instead been selected to surface the spectrum and breadth of diverse perspectives in relation to the topic at hand. It should be noted that the decision to give preference and space to PLHIV and civil society organisations in the interviews means that the synthesis does tend towards a civil society perspective, although other perspectives have been included. At the same time, most interviewees straddle a range of identities and affiliations. For example, many of the academics and clinicians are also activists, while government representatives are also clinicians or scientists.

This document takes you, the reader through views expressed on a wide range of themes. Given the degree of nuanced detail in the quotes, some sections may be of less interest to you. The synthesis report caters for selective reading. As you read this report, you may find yourself searching for the perspectives that confirm

your world view, and be tempted to dismiss those views that you deem as incorrect, or those with which you do not agree. In this regard it may be helpful to remind yourself that “this is what the HIV system looks like to this person, from their perspective.” Observing your own responses to the quotes you have read can also be an important source of information. Which views are you comfortable to read and which elicit a strong response in you? What views strike you as stale and which seem newer and fresher? Is there anything you are seeing more clearly as a result of the synthesis report?

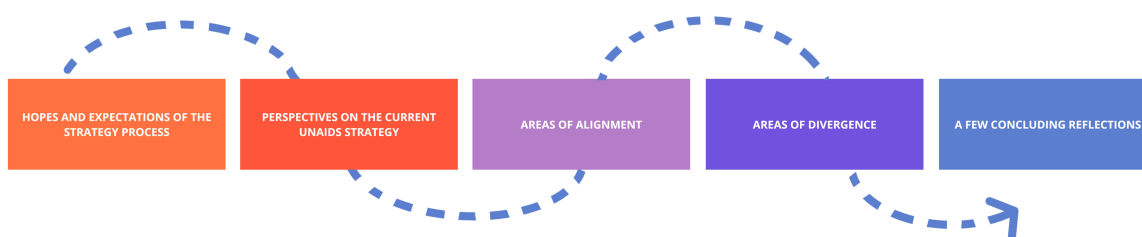
One thing that may strike you in reading the report is a certain level of confusion around terminology, language and framing. For example, when people refer to the “strategy”, are they referring to the “UNAIDS strategy” or the “global AIDS strategy”? Or when respondents refer to “UNAIDS”, do they mean the Secretariat or the Joint Programme. There are many other terms that have a range of meanings for different respondents, such as “collaboration” or “integration” or targets. This document does not attempt to resolve this confusion or define the terms that are being used by respondents, but rather presents this messiness and confusion as it currently exists in the system. Because of the best place to start a multi-stakeholder dialogue is from engaging with the reality as it is, rather than from how it should be.

7. Report structure

Given that one of the key outcomes of the first participatory workshop is further clarity on the strategic option to be decided by the PCB in September 2020, this report has been structured in such a way as to support these deliberations. Section 2 highlights what participants have articulated about their hopes and fears for the strategy process itself. By placing this section up front, the report signals to the interview respondents and readers alike, the commitment to transparency of views and willingness to engage in an honest and open reflection of the past, the present and what this might mean for the future. The following section provides an overview of overarching perspectives on the current UNAIDS strategy. This is followed by a section focusing on emerging strategic themes where there is high-level in-principle agreement. The second last section highlights strategic themes where there is significant divergence in opinion.

Given the wide-ranging perspectives on both the challenges and potential recommendations, each of the substantive section work with the range of suggestions and viewpoints as potential strategic questions. Each strategic question is followed by quotes (some questions have more quotes than others) that speak to some of the tensions, dilemmas and potential nuances of each question. These quotes are not annotated, as they provide a provocation for dialogue and engagement in the workshops and other engagements during Phase 2 of this process. Please note that these questions are not exhaustive. Given the nature of the workshops in coming weeks, additional strategic questions will surface.

A few emerging reflections conclude the report. These are based on the consolidated strategic questions as well as the process of drafting this synthesis report.



Hopes and Expectation for the strategy process

1. Overview

During the interviews, respondents were invited to share their expectations about the strategy development process. Given that this report is a component of this process, this feedback is included at the beginning of the report, as it provides guidance for the report itself, including the request from respondents for transparency and the willingness to engage in deep reflection and learning from both the past and the present and what it might mean for the future.

2. What was actually said

On participation and engagement of new and unusual stakeholders

“I don’t know how much the consultation is going to seek out inputs of people who are likely somewhat antagonistic, in the sense of other agencies who are competitive with UNAIDS or maybe perhaps have negative views of its work, but that is always useful to really be able to understand and build in the counter-views to those of us who are more champions of UNAIDS.” (individual expert)

“How can we get new people with new ideas, with new energy? What for example would be the role of young people, young scientists, what would be the role of the private sector, the broader women movements and feminists? You know like getting out of the normal, those that we know, but getting new brains and brands on board.” (PLHIV network)

On on-going engagement and participation by stakeholders in the strategy process

“I think you are doing great, the way that you are engaging different stakeholders on different levels, and what will be good is that I know we will have feedback about the strategy. I think it will be good to have an opportunity to see ... how people can still input or provide comment on the result of this consultation... I really look forward to seeing what the result of the consultation will be or how the process can be more inclusive, as it is now.” (PLHIV network)

“How do you ensure that people feel like they are going on a journey and not just giving a download from their brains and then they don’t really know what happens. So it is about a whole journey, because that is how you bring people along.” (Donor)

“Where stuff hasn't been take on its always good to circle back to those that felt really strongly about a certain view - its time consuming but otherwise you can risk losing people along the way.” (Donor)

On trust and transparency

“There’s this advisory group to the Executive Director that was appointed early on ... how was the advisory group fitting in with your process and the strategy review process? Because that advisory group produced a report in February and to my mind laid out a

path. What I don't want to be the case is that you and I are wasting our time because there's a parallel process. And what we're doing is window dressing for the appearances of rigorous transparent process... Where's the transparency and how does it particularly fit? ... I don't like to be a part of a show.” (Civil society organisation)

“If we could understand the 50 or 80 people selected for qualitative interviews, if we could understand the 30 or 40 people for the participatory workshops, I think that would open up a huge amount of trust and space for all of us to speak openly. At the moment in my sector, we're all trying to work out what's happening and who has the ability to participate because it's quite closed.” (Civil society organisation)

“Decades of the HIV response have established the importance of key populations, people who use drugs, sex workers, LGBT groups, being at the table. And it's been a long time since I think any of us have thought that we have to fight internally within UNAIDS to have our voices heard.” (Civil society organisation)

“If you know the budget, if you know the working plan, if you know the indicators and what the actors expect to produce during this period of time, this money and this political influence, then you can start asking the right questions.” (Key population, women or youth network)

... especially as it relates to decision-making regarding the next strategy

“UNAIDS needs to be really open and to acknowledge that health is political ... And so when you get the PCB Member States together, making decisions, passing this strategy, we need to acknowledge that each member state comes to the table with their own political agenda. And we need to be able to work through that in a transparent manner, and to find some sort of mechanism to prevent vetoes on the basis of country political positions.” (Civil society organisation)

“My worst fear is that the strategy has to be approved by the PCB and that is Member States and they are being particularly difficult at present around community and the role of community.” (Key population, women or youth network)

On the willingness to reflect and learn

“I would think this is the beginning of a good journey that shouldn't end with a report and then it is business as usual. Hopefully this kind of introspective, interrogative, iterative process will go forth. ... I think also being open to critique, so that people feel like UNAIDS is us, and us is UNAIDS ... that it really does feel like our vehicle for moving this thing forward. And by 'our' I mean the world at large, the people who care. I think that would be really very, very important to sustain it. And the movement.” (Academia and research)

“I would also really hope that UNAIDS together with all co-sponsors and everyone else really looks deep into what didn't work in the last strategy, really identifies the gaps, really analyses why it didn't or did work ... So we don't come up with an yet another new strategy that comes up with targets and comes up with goals that have no reality in what happened in the last five years, what happened in the last 10 years.” (Civil society organisation)

On having the important conversations

“So my highest hopes would be that ... we manage to get ... people, engaging in a really meaningful way that is getting people outside of their institutional mind-sets and positions – which is always really hard because people come with all their baggage, and I guess if you are talking about governments they come with their government lines. I don’t know how you ... can get people ... putting all of that aside, and thinking about what is most important – I hope you can get that.” (Donor)

“If this strategy is going to be done at all, that it has to go to the complexity, it has to put on the table the big questions because without doing that I think you will just disappear in the largeness of the big questions that the world is grappling with.” (Civil society organisation)

On collective ownership of the strategy

“We must be very clear that this is not UNAIDS Secretariat’s strategy, it is the strategy against HIV of everyone, it belongs to everyone. It does not belong to - or even the responsibility of - 600 UNAIDS staff and the executive director; they can do very little, they can only advocate! The action is us, how can we make people feel that ‘this is our strategy!?’” (PCB member)

“Really trying to create that sense of excitement and thinking about how do we co-create a better future.” (Donor)

Perspectives on the current UNAIDS strategy

This section synthesises a range of perspectives on the current UNAIDS strategy as a whole, as well as more specific views on prevention, testing and treatment and stigma and discrimination, which form the basis of the “Three Zeros” in the current UNAIDS strategy. The headlines provide a snapshot to the verbatim quotes that follow each section. As mentioned in the introduction, these are not exhaustive perspectives, nor do they represent majority views. Rather they have been selected to offer a window into how a broad spectrum of respondents from across the HIV/AIDS system are viewing the current strategy, including some of the key challenges, as well as the key strategic questions that emerge when these perspectives are placed alongside one another.

1. Overarching perspectives

On strategy and implementation

“The strategy is great ... it doesn't translate into action on country level. And at least for me, it's the biggest problem.” (Civil society organisation)

“My concern is less about the strategy but the downstream implementation.” (PCB member)

On progress

“So as someone who was on those clinical wards, as someone who lost people in my family and looking back over the last 15 years broadly, there has been great progress, whether we are talking about new infections, whether we're talking about deaths or whether we're talking about discrimination.” (Academia and research)

“The fact is that AIDS has become endemic. At this point 1.6 million persons per year are being infected and 600,000 are dying.” (Academia and research)

“It's better than 30 years ago but there is the perception that it's over and hence there is a lot of complacency and the voice about AIDS is not there. It's no longer headline news. That complacency is what I'm worried about and that's why we need UNAIDS.” (Academia and research)

“Differing levels of progress in groups and geographies ... my observation as to what is probably driving that is unfortunately less around the science and more around the politics, culture and religion, which I think ultimately play into decisions.” (Private sector)

On perceptions and complacency

“There is a sense that it is a kind of a problem we have resolved at least in the north to some degree.” (Civil society organisation)

“What is happening in some of the countries in Africa is from the community side the general feeling is that HIV is no longer a problem because that perception of risk is really no longer there.” (PCB member)

On implications for the next UNAIDS strategy

“UNAIDS had remarkable results with the current strategy. We expect and don’t doubt that the next one will be as robust, ambitious and successful.” (PCB member)

“We don’t need to reinvent the wheel for this new strategy. I think that it will be very, very, very important to keep the strong areas identified in the last strategy. It was not a bad strategy.” (Civil society organisation)

“We are not short on ideas but short on how they need to be executed by the right parties.” (Civil society organisation)

“The last 10% is less reachable in a way... if you talk about key populations, those are the most hidden, hard to reach key populations. So the so-called normal things that you are used to doing in the HIV response, they might not work for them– and most likely they don’t work for them because if they did we would have already reached them. ... So it is really thinking about new approaches that were not even considered before ... it has to be a completely different strategy. We have to look into those niches and be creative.” (Civil society organisation)

2. Perspectives on prevention

Overview

Prevention has fallen off the agenda

“Ten years ago every meeting, we talked about turning of the tap and 50/50 prevention, and then it's gone.” (PCB member)

Existing commitments and targets have not been met

“Prevention is failing everywhere in every country.” (Civil Society organisation)

“Before Covid-19 we have abysmally failed to deliver on our HIV / TB prevention targets.” (Civil Society organisation)

“We should have been at about 500,000 infections in 2020, we're still closer to 1.5 million. So with the other targets we're off, but not as off as we with prevention.” (Academia and research)

“It's a pity that not even the commitment of investing 25% of the national budgets for prevention that is this strategy is part of the 2016 declaration of commitment. We are far from that yet.” (Civil Society organisation)

In some regions, infection rates are increasing

“We know, to some extent, 50% of that is in Southern Africa. We know that we have emerging epidemics in the Middle East and North African region. We know there are issues in Eastern Europe and Central Asia. So, and we know that they pockets of high rates of infection in particular parts of other industrialised countries.” (Academia and research)

Prevention needs special attention in the next strategy

“How do we ensure that prevention get to the top of the agenda again?” (Individual expert)

“Please God, let someone pay attention to prevention. Everything in the last 5 years is about treatment.” (PCB member)

“We need to invest in prevention, rather than waiting for people to get very sick.” (PLHIV network)

Challenges

An HIV vaccine remains elusive

“There has never been a disease that we have effectively tackled that doesn't have a vaccine or a cure.” (Academic and research)

“We just had a failed HIV vaccine trial. HVTN702 was a large efficacy trial of a vaccine. It was developed specifically against the virus circulating in Southern Africa. All the trial sites were in South Africa, 5,000 people enrolled. Unfortunately, the vaccine didn't show any effect.” (Academic and research)

Biomedical prevention solutions have not been taken up as much as was anticipated

“PrEP has not delivered as a prevention tool to the extent that we hoped it would, particularly for women and girls in sub-Saharan Africa.” (Academic and research)

“We couldn't widely implement the PrEP yet. Government endorsed it, but the main issue is that we didn't have adequate funding to operationalize PrEP to expand for all key population at the moment.” (National Coordination Mechanism)

“Most women don't know much and they don't receive adequate counselling. EMTCT is not working well and Nigeria has 35% coverage. That is shameful.” (PLHIV network)

'Treatment as prevention' is diverting attention from primary prevention

“There were challenges in the call for 90-90-90. It achieved significant success on treatment. But I think there are unanticipated side effects, particularly related to investments in prevention and primary prevention.” (National Coordination Mechanism)

“In terms of the Caribbean is that there we have made significant progress in the area of treatment and providing antiviral therapy for people living with HIV. The consequences of that, however, is that there has been a significant shift away from prevention.” (Key population, women or youth network)

A reluctance to pay attention to key populations

“I sit on the Prevention Coalition Working Group representing key populations. And I remain shocked at the lack of attention to the group of people who now represent 53% of the infection- and that is the key populations and our partners. If you look at the Prevention Coalition, that has remained the one that is increasing ... we have managed to plateau in some of the other vulnerable populations.” (Key population, women or youth network)

“We won't get anywhere if we can't stop young women, sex workers, men who have sex with men, trans people, and prison populations from getting infected. We have to keep focusing on them.” (Individual expert)

A reluctance to commit to harm reduction for people who use drugs

“December last year, we saw pushback from a number of [UNAIDS PCB] member States on the use of the term harm reduction, which represents a two decade regression on progress that's been made.” (Civil society organisation)

“We're always saying: be guided by science, yet, we can't be brave enough to mention harm reduction for fear of upsetting the US.” (Academic and research)

Sexuality education is not an option in many countries

“I got HIV diagnosis at the age 18 ... In [interviewee's country] it's not really very much taught at school, sex and drugs, they don't have a curriculum for that. ... which means I wasn't taught anything about it at school which apparently lead then to some behaviours which is why I had the HIV infection by the age of 18.” (PLHIV network)

“Sex education is an issue. Radical groups and religious groups influence our system in Ukraine and Russia. Parliamentarians don't understand why it's needed. The quality of information about our bodies, our health, our access to support from parents. If we look at relationships between teenagers and parents, it's not a good relationship. It's a real problem.” (Key population, women or youth network)

“The other area that was stuck in all these years, we never were able really to advance is the comprehensive sexual education. Without teaching girls and boys comprehensive sexual education, gender equity, and so on, we will continue with this unsustainable system, which is more people get infected, who need to pay for treatment more. It's unsustainable.” (Civil society organisation)

It is hard to monitor and measure prevention

“One of the difficulties that we have is that we cannot count prevention... I cannot count the amount of funds that are used for prevention, at least not in my country, because it's mixed with so many things that you cannot separate.” (Civil society organisation)

“There is a different dynamic around mobilising money for prevention than for treatment... The metrics of success are easier when talking about treatment. You have a starting point - and outcome. With prevention you're always measuring something that didn't happen.” (Donor)

Strategic questions

(When) will we find a vaccine?

“We need to manage expectations about the biomedical response. There was a bizarre sense at the Rwanda meeting that we would have a vaccine quite soon.” (Donor)

“Even if we significantly reduce the disease there will continue to be vulnerable people who will get infected. Only with a vaccine will we be able to eliminate the disease.” (PCB member)

“The development of a vaccine: after 30 years we still haven’t found a vaccine, while in 4 months it seems we will have a vaccine for Covid-19.” (PCB member)

“We need to use the urgency that COVID has provided in the public thinking to drive additional funding and research for an HIV vaccine.” (Individual expert)

Do we adequately understand why prevention is failing in each context?

“We need to know what is really happening in each place? Is prevention failing because of a lack of condoms? Use of condoms? Or are there some super-spreaders? You need to analyse very closely.” (Private sector)

“But when you look at prevention, you actually don't know who is most at risk because those most at risk just don't even perceive themselves to be at risk. Or those who perceive themselves at risk may face other barriers and enablers. So that's a much more complicated challenge, not an insurmountable one, but a little bit more complex and complicated. You don't have this magic bullet or silver bullet or one size fits all. You have to be thinking and solving problems at a local level. ... it's a very customised, differentiated approach that you have to take.” (Academia and research)

“Lots of money is being spent on huge prevention campaigns, but it’s not effective: we know these things don’t work. There’s a lack of ideas for how to spend the money correctly and effectively.” (Private sector)

How to adequately elevate the importance of HIV prevention into the public arena, especially in political and social contexts where open references to sexual and reproductive rights, health and sexuality remain taboo?

How do engage your younger generation, to ensure that you continue taking preventative measures?” (PCB member)

“Massive campaigns that actually help people to understand what it means to be safe, what it means to conduct their sexual activities safely, a comprehensive sexuality education, sexual health and reproductive health information be accessible to young people without fear or favour. Recognising that young people have agency, they can make decisions once they get the information.” (Key population, women or youth network)

“Achieving prevention requires combination of having the vaccine and also people really understanding the risks and not putting themselves in the way of those risks - particularly young women. Knowledge about HIV and how to prevent should be universal.” (Individual expert)

How to make an investment case for prevention?

“A lot of them are going to live to be 80 years old but they're going to be on treatment for the rest of their lives, the cost to the system of not bearing down on the prevention and services that could have prevented that.” (Civil society organisation)

“If you start with 20% of your staff seropositive, and then you add 1% every year. How sustainable is that? You might be able to keep people alive, but the cost of the treatment will be growing. It all starts on prevention.” (Private Sector)

“If you back off of kids broadly, if you back off on services ... as they did in Homa Bay, in Kenya in 2019, there were 700 new paediatric infections. All of those were unnecessary and preventable, but there was a pullback, and that's 700 kids.” (Civil society organisation)

“How can we sustain our current achievements in prevention and treatment without having adequate funding in the next 3-5 years? Global Fund is our main funding partner and have offered a contribution to 2023, but it might reduce after that. If we cannot get adequate funding, then we'll suffer and we won't be able to sustain our achievements.” (National coordination mechanism)

How to adequately prioritise and fund different aspects of prevention, especially the more contested aspects like sexuality education and harm reduction?

“Education is a big component for prevention but still it's also relying on foreign funding situation.” (Key population, women or youth network)

“It's a big shift to go from for a national government to go from having international donor funding for the HIV response, to having to deal with, sometimes the sensitive issues of harm reduction and other HIV prevention services themselves.” (Civil society organisation)

“We know that around the world now the most recent data is the majority of new infections are happening amongst key populations. And so we know that now is a time for UNAIDS to turn its attention to a harm reduction response, to people who use drugs and to HIV prevention amongst other key populations.” (Civil society organisation)

“In HIV because you're talking about sexual practices, you get into areas of data that people feel uncomfortable talking about. The prevalence of heterosexual anal sex, for example. Governments and people feel uncomfortable talking about those topics. But, you're going to need to understand these things if you are going to really have effective prevention strategies.” (Donor)

“Harm reduction funding for the past decade ... had an 87% shortfall of what we needed to actually mount a sufficient response for people who use drugs.” (Civil society organisation)

How to ensure that the prevention responses address the root social drivers of new infections?

“We need to have a very clear focus on maintaining a prevention agenda and maintaining sufficient funds. To actually have an impact on prevention isn’t just biomedical PrEP and male circumcision. And I think that needs to be focused on and those that are most vulnerable ... the evidence is there: the majority of new infections are amongst key populations and the sexual partners that they have. So it doesn’t make sense for us not to actually start looking at how do we stop those new infections with as much vigour and enthusiasm as we have with other groups.” (Key population, women or youth network)

“You can do test and give treatment, and by doing so, you can prevent deaths. But these are technical solutions that can be implemented by experts. And people can take the treatment but it’s still not addressing the root causes of new infections.” (Private Sector)

“Our strategy was to have more people tested and on treatment, but there wasn’t as much emphasis on inequalities and barriers of how people can access the testing and the treatment. As a result of not addressing social issues, inequalities and barriers, you can’t succeed at eliminating new infections and deaths.” (Civil society organisation)

3. Perspectives on treatment

Overview

There has been real progress overall

“30 years ago, life expectancy was 5 months after being diagnosed with AIDS. Today life expectancy for people with AIDS is almost as high as for people without AIDS.” (PCB member)

“So we've seen how treatment access, for example, and the change in AIDS from one that was inevitably fatal to one that's chronic and manageable gave hope to a lot of people.” (Academia and research)

“I think overall we've made remarkable progress and I think that's something that we need to acknowledge. Nobody would have even dreamed that we would be able to as a global community to scale our treatment to the extent that it has been done. To be able to get millions and millions of people on treatment, to expand the lifespan, have a baby be born without HIV infection, have people living with HIV now have the opportunity to have almost a normal lifespan. I think these are very critical advances that have happened globally.” (Academia and research)

There has been progress in certain regions

“If you think back to 2000, when the 13th international conference was hosted in Durban, it had only been five years since triple therapy was available and accessible in industrialised countries, but on the continent, 70% of people living with HIV didn't have access.” (Academia and research)

“In the Africa region, access to treatment made a miracle - people are able to live longer healthy lives.” (Civil society organisation)

But many people are not on treatment

“So we have something like 24 million people on treatment, but we have nearly 38 million people who are living with HIV. There's a big gap in treatment, which is who are we missing? Where are that 30 to 40% of people who need treatment and are still not on treatment and why are they not on treatment?” (Academia and research)

“I thought that if we could bring medical treatments to Africa, it would solve mortality problem. But that was a mistake, because we still have a lot of people dying.” (Academia and research)

“The good news is that there is a real decline in the people dying from AIDS, but the reality is far from the rhetoric of UNAIDS and the reports are over-optimistic.” (Academia and research)

Challenges

Access to treatment is still an issue for many because of financial and physical challenges

“So rich gay men in urban areas around the world have access to treatment. Wealthy straight men and women in capitals of Eastern Southern Africa have access to treatment. Rural people, people who are living in poverty, people who are LGBT and living in poverty... these intersecting realities are where the epidemic is right now. And that makes it harder.” (Academia and research)

“The ability of people to access this medicine. It is a challenge in some places, financially and physically problem to have access to these.” (Civil society organisation)

“ARV drug is now free but is still inaccessible in West Africa.” (PLHIV network)

The unpredictability of the financing landscape for the global AIDS response presents challenges in many countries

“I'm afraid of dying. I'm afraid that maybe there will not be drug tomorrow because our government in West Africa region, most of the country of West African region, including Nigeria where I'm staying, they are not investing money in the treatment of people living with HIV. It is donor driven, Global Fund, American government.” (PLHIV network)

“There is still a problem of accessing medicines, especially for middle income countries. And that's where it's becoming a bigger and bigger portion of the budget in middle income countries to pay for HIV treatment, because they're not able to access some of the lowest prices available because of intellectual property rules.” (Academia and research)

“We made a multi billion dollar – which we now can't back away from because we have millions of people, now close to 60% of all estimated of all people living with the virus on treatment, and they're going to have much longer life expectancies and they are going to need therapy for many years!” (Academia and research)

“We still have 1.5 million infections every year ... but we can't maintain the intensity that we have seen in the last 30 years. There aren't insufficient resources in the world... We have to figure out how we do different things in different parts of the world now.” (Academia and research)

Issues around stigma, discrimination and criminalisation mean that people are afraid to come forward to be treated are not able to stay on treatment

“We thought that with treatment, stopping mortality, the stigma would die too because the fact that there is a treatment, would normalise AIDS, but having treatment hasn't ended either mortality or discrimination. The mistake I made was that I didn't understand the stigma is not about AIDS but other things: sexuality, race, etc.” (Academia and research)

“People tend to wait until they're very sick until seeking treatment. People don't get tested. We're losing the spirit of testing from 15 years ago. There were massive campaigns for people to know their HIV status as early as possible.” (PLHIV network)

“With the swing to the political swing to the right, key populations with HIV, gay men or sex workers, for example, will tell you ‘We don’t like going to the clinic. We’re treated so badly. We don’t even get to ask questions.’” (Individual expert)

“What the AIDS pandemic has made very clear is that whether you care about human rights or not, even if you’re slightly to the right of centre, you have to have human rights in order to beat AIDS. So whatever your moral and ethical perspective, if you chase people into hiding, they don’t get their treatment and they don’t test.” (PCB member)

There are major concerns that disruption in treatment, particularly because of COVID, may lead to drug resistance

“Drug resistance is enormously worrying. It’s related to disruptions of services and so on. If drug resistance contributes to increase at the rate that is in certain areas, all of the gains are lost. The cost of services becomes so much higher. The infection rates will be higher. The death rates will be higher. I think that’s a huge risk.” (Individual expert)

“In the last two years we have had 110,000 people come off therapy in Venezuela because of a political collapse and a collapse of the healthcare system.” (Academia and research)

“As a result of COVID, things have changed, it’s going to be worse. Because of financial problems people have stopped taking treatment because were afraid of going to the hospital, for example.” (Private Sector)

“What happened at the beginning of the AIDS crisis is happening now. Back in the late 1990s people who got HIV medications would sell them because otherwise they couldn’t afford food. What’s happening now with COVID is the same. COVID has increased precariousness. A lot of our HIV positive friends have stopped taking their HIV medications because they don’t have food and the medications are strong and burn your stomach and give you a headache if you don’t have enough food.” (Key population, women or youth network)

“And then of course, even the impact on retention in programmes, we’re beginning to see this already.” (Academia and research)

Paediatric treatment is a particular challenge that is not receiving sufficient attention

“Paediatric ARV is not readily available. Testing for babies that are born to a HIV positive mother is not instant. Prophylaxis, is not readily available... Paediatric ARV treatment is not being taken seriously.” (PLHIV network)

“As we know in Uganda’s case, and I think it’s true for many parts of Africa, access to treatment by paediatric groups, has lagged behind adult groups, for many reasons ... just to give you an example, because children, in the phase where they are rapidly growing up, their weight is changing. And so their treatment dosages are going to be fairly rapidly evolving. And that complexity has always intimidated healthcare workers and led to a bottleneck in treatment, but also formulations. And the fact that these formulations, again, you’re talking about syrups and how you measure them and how they keep changing with the weight and how they’re difficult to take.” (Academia and research)

“Kids here are dying of AIDS more than anything else. Our treatment rates are appalling ... For me this is our biggest failure.” (PCB member)

COVID has the potential to roll back the gains that have been made in treatment

“Emerging research results show increased death and 20% setback in terms of achieving the targets primarily around HIV testing. Testing has decreased.” (Civil society organisation)

“In the past three to four months, we've seen significantly decreased HIV testing within the US as people have not been able to access those services as much.” (Civil society organisation)

“The procurement of ARVs in lower middle income countries has been affected by Covid-19 because the supply chain includes importation of drugs has affected.” (Civil society organisation)

Just last week there was an ARV shortage. Why? Because the flights have been cancelled.” (Individual expert)

“Essential services got restricted. So now what that means is if you have chronic conditions, not just HIV, TB, and hypertension or diabetes, or if you were pregnant, you're not going to health facility.” (Academia and research)

Strategic questions

(When) will we find a cure?

“We can't end AIDS until we have a vaccine and a cure.” (Academia and research)

“I think we shouldn't stop discussing about new innovations around new drugs, but also more funding for HIV cures, especially at this point of competing research priorities and clinical research priorities.” (Civil society organisation)

“If there isn't the likelihood of a vaccine or a cure for years if not decades, then the ability to sustain the response is going to have to evolve, and if it can't depend on traditional sources of funding, then it is far more important as part of the agenda to figure out how Kenya, for example, can go from being 80% dependent on external sources for their HIV response, to only say 20% over the course of five to seven years.” (Civil society organisation)

How to make treatment more affordable and accessible to more people?

“I think we have to be very aggressive and supporting of countries and using their leverage under TRIPS to use compulsory licensing and whatever it takes in order to get access for the most marginalised populations and really call out any sort of trade agreements or any

movement that goes toward lessening those rights, or it goes toward empowering pharmaceutical companies to continue to set whatever price they want without any sort of a guarantee to access for marginalised populations.” (Civil society organisation)

“I think it was 2015 or 16, [the previous Executive Director], because funding constraints, decided to cut the only position he had at the headquarter that was dedicated to follow up on TRIPS, on intellectual property. And it was not necessary of course, because it was only one position, you know, won't make any difference in the entire budget of UNAIDS, but it was a political message.” (Civil society organisation)

“As we move forward, investment in ... affordable medication is pivotal in the response.” (Key population, women or youth network)

How to improve treatment adherence and avoid dropouts especially amongst vulnerable populations, under disruptive conditions?

“One aspect that needs to be focused on as a priority is the retention and adherence to treatment, reducing rates of abandonment.” (PCB member)

“There also needs to be attention paid to follow up and retention in the health system. A lot of attention is paid to what happens when you're actually there receiving treatment. The follow up is important.” (Individual Expert)

“When will we have simpler and more potent treatment that decreases the rate of abandonment?” (PCB member)

How to leverage opportunities or innovations from the COVID-19 crisis?

“The adaptations as a result of COVID are really quite striking and they're coming fast and furious; like multiple dispensing ARVs differently than you did before... There's a lot of remote counselling and tracing of patients, sending reminders. There've been creative ways of getting ARVs, clustering geographically, and then someone on a motorcycle can get out and make delivery.” (Civil society organisation)

“We've asked for takeaway doses for a long time, but I think with harm reduction centres and treatment providers, they're like, ‘no people who use drugs need to be surveilled and controlled and all this stuff’ ...So with COVID, they did start to listen to communities.... a lot of countries, in Eastern Europe as well, did change some of their policies... So the concern now for us is being able to document some of that and sustain those changes.” (Key population, women or youth network)

“If we ended up like New York and Italy... clinics and hospitals will become vectors for disease ... So services like HIV testing, ARVs contraception will have to find other spaces... We're going to have to push very hard for issues like ... being able to do their own self-testing, self-injecting contraception, even task shifting on ARVs, which at the moment is very tightly controlled in countries should be loosened up to allow people who are not ill to get services. That's quite likely to happen in the next year in this region.” (PCB member)

“A crisis like this is going to force innovation and change and ideas. Once we turn the corner on COVID, folks will identify: ‘we didn’t think to do this four months ago, but now that we’ve been doing it for four months, these are improvements in efficiency or effectiveness and it leads to more patient-centric care as a result of the changes.’” (Civil society organisation)

4. Perceptions on stigma and discrimination

Overview

HIV infects and affects the most vulnerable and unwanted communities in society

“HIV infects and goes for the marginalised, unloved, unwanted communities.” (Academia and research)

“We won’t address this crisis until we reach everyone, without discrimination.” (Individual expert)

“Today when we look at global spread, we will see that more than 54% are of new infections are in key populations.” (PLHIV network)

Stigma, discrimination and persecution of key populations remain major problems in many countries

“Just 2 weeks ago a gay guy was killed. He was stabbed 87 times and it wasn’t treated as a hate crime.” (Key population, women or youth network)

“There’s extrajudicial killings [of PUDs] going on. Different countries also favouring compulsory treatment and detaining people and compulsory detention centres.” (Key population, women or youth network)

“When I mention HIV related stigma and discrimination, that covers violence and abuse against women, and girls and children as well.” (Civil society organisation)

There is a huge gap between rhetoric and action in the HIV response

“Everyone is talking about it [eliminating stigma and discrimination] but on the ground it is addressed as a formality.” (Civil society organisation)

“In 2010, when we reiterated the language of the 10 reasons why human rights need to be at the centre of the HIV pandemic. ... A real movement was built to say: this is unacceptable. Now it’s become so mainstream that it’s almost meaningless. So people are saying the right things but not necessary doing the right things.” (Civil society organisation)

“The UN has set a lot of standards and commitments around addressing stigma and discrimination, but I think we’ll never achieve the end of AIDS until we achieved zero discrimination and we achieve it based on evidence and not just based on the number of how many times you’ve said it in one statement.” (Civil society organisation)

Addressing stigma and discrimination is crucial to the HIV response

“Discrimination makes effective prevention and access to treatment more difficult. Because people on the ground are ashamed, they will not come forward, and funding will not be

there because those in power don't want to waste their precious tax money on 'those people'." (Academia and research)

"We did a major report it was released in the Lancet in 2014 at the international AIDS conference, where we looked at all the different prevention and treatment options for sex workers. And one of the things that came out of that work was that the single most important intervention... was decriminalisation." (Academia and research)

"We are still in countries that penalise homosexuality, people who inject drugs, instead of accompanying them. These people are not going to stop, they are going to hide and will continue to be infected and to infect others because we know that when you are not treated well, the virus will continue to spread. My frustration is that, today, if we all got together, and instead of penalising we support and ensure that everyone has the right to care and prevention and is treated, we would eliminate HIV." (PLHIV network)

Challenges

HIV cuts to the heart of morality questions

"Nobody wants to know about sex workers. Nobody wants to know about men who have sex with men, and nobody wants to care about all those things. You are seen as you shouldn't be existing. So it is the moral question that has been placed on HIV, the moral issues, and who is good and who is not good." (PLHIV network)

"The notion that those people living with HIV are guilty because of their own sins... this is also the reason why the majority of the society thinks that they should bear this burden by themselves without essential help from the society, from the state." (PCB member)

"If someone believes that, for example, homosexuality is wrong from God's perspective, they're not going to change that belief in 10 years." (Civil society organisation)

"You cannot leave someone behind if you don't consider them there in the first place." (PLHIV network)

HIV/AIDS-related stigma and discrimination intersects with widely accepted social, religious and cultural norms

"AIDS itself reveals existing fault lines and discrimination in society. AIDS has not created them. These discriminations include sexual orientation, discrimination from other minority groups etcetera... it's a bit different from society to society." (Individual expert)

"It is really not a simple area to address because anything that relates to norms, to people's beliefs, to culture; it is probably the toughest to change and it requires the most effort and time." (Civil society organisation)

“We have a very macho society in Latin America. I saw the direct link to sexual abuse and domestic violence. Also a connection to being vulnerable to HIV infection through violence and because women’s sexuality is taboo.” (unusual partner)

“Attitudes towards, for example, men who have sex with men in sub Saharan Africa are highly entrenched. Sometimes I'm part of discussions where people provide views and you feel that they are really visceral, they're not cerebral, they're at some visceral level, people are very diametrically opposed to the gay culture.” (Academia and research)

Stigma and discrimination play out within the HIV response also

“I get into conversations with people where I remind them consistently... that we are also adolescent girls and young women, but we are never, ever included in the programming that is done for adolescent girls and young women. So if you look at DREAMS, and the huge amount of money that has been invested, sex workers were explicitly excluded from most of the DREAMS projects.” (Key population, women or youth network)

“I've been very fearful. I've been very alarmed when I heard the same arguments to keep that [HIV criminalisation] law coming from people who are running respectable HIV organisations, respectable human rights organisations. To me that tells the story of how deep stigma is running.” (Key population, women or youth network)

“But as women ourselves there is also violence amongst us depending on who you are, how you identify. I know people frown on LGBT women when we are within spaces where its women who are positive. I hear the subtle and sometimes not so subtle...People still condemn, look down upon them in discriminate and stigmatise.” (Key population, women or youth network)

“Winnie, I know she is a feminist and she's been very vocal about that and there's a lot of focus on women and adolescent girls, but I think, unfortunately there's this weird disconnect, like this assumption that when we're talking about women and adolescent girls that it's not women whose drugs, it's not the bad girls or sex workers, it's not transgender women.” (Key population, women or youth network)

Powerful religious conservative elements in society actively fuel and promote discrimination.

“Where governments are conservative or have ideologies that appear to be conservative, HIV thrives, because they don't provide services, they don't call it out, they don't provide the resources and they drive it underground through bad laws and bad policies.” (Academia and research)

“The biggest issue in Latin America is the relationship between government and religious entities. In some cases religious entities have more power than government; the churches have the power to stop the conversations (about access to health care, about safe sex).”

“The church ... they have the power along with the government, that is the biggest issue that Latin America has.” (unusual partner)

Vulnerable groups are political currency in many countries

“If you look at the score of elections, in the majority of countries, from our region, you will see there were almost no examples when one or another candidates won the elections with 1%. It's always about like 70 to 30, 80 to 20. So this is the situation that makes the voices of minorities marginal to the interest of those who gained the elections: one, two, three, four, five percent do not matter.” (PCB member)

“The marginalised communities that are disproportionately affected by HIV tend to not be the favourites of authoritarian governments.” (Civil society organisation)

“In fact, we end up being political currency for them because at any given time, if they are challenged and their political dominance or the way that they running the country, they can always point to the brown people, the black people, the queer people that people are suspicious of because they are different because they're in a minority populations and use that to galvanise, and authoritarian base and, and continue to blame us.” (Civil society organisation)

Criminalisation is one of the great impediments to effectively tackling the HIV epidemic

“So long as there are criminal laws against sections of the community who are susceptible to HIV, you will have discrimination. That discrimination will be supported by certain groups, such as religious groups. Which makes it much more difficult to reach out to and engage people most in need of support and assistance.” (Individual expert)

“A lot of the time for people who inject drugs, law enforcement wait outside harm reduction centres, hoping to pick people up because all the times they'll have quotas for arrests and things like that. And waiting outside of harm reduction centres, is an easy way to meet those quotas.” (Key population, women or youth network)

“A Palestinian guy, he was born in Saudi Arabia, lived all his life in Saudi Arabia, he's an engineer, he had good career in Saudi Arabia and he never went to Lebanon, he's originally Palestinian. He got diagnosed in Saudi Arabia. For sure they cannot send him to Palestine because you know the situation in Palestine. They sent him to Lebanon. He was sent to live in a country that he never visited and he has nothing, he has no house, no family, no friends, no one. All of a sudden he is at Beirut airport, and definitely in Lebanon he cannot work as an engineer because he's not allowed as a Palestinian, he's considered a refugee so he's not allowed to work as an engineer. So basically despite his degree, he cannot work anything, he can work in professions that does not require degree - for example, handy positions which definitely someone who is well educated and has a dream to improve in his engineering career will not accept to be able to do this kind of work.” (PLHIV network)

Discriminatory, uncaring practices continue even with enabling policies

“We do have the regulations, we have the laws: no discrimination or on human rights. But the people treat people not as people.” (Individual expert)

“New nurses who have not been trained and coming to the facility. They are judgemental and nurses disclose who is positive.” (PLHIV network)

“The relationships between doctors and patients is still challenging. For example, a doctor will give you medicine and say, you should take it and then you should shut up. In the fight against AIDS, I was more informed than the doctors. Some were honest about what they didn't know, but some didn't acknowledge that they were incapable of giving good care, and gave whatever treatment they wanted because the word of the doctor is the word of the gospel.” (PLHIV network)

There is a lack of political leadership to effectively address the issue

“UNAIDS has become more reticent about being really vocal and being the honest broker for key populations.” (Key population, women or youth network)

“The third partnership that was formed in 2018 was significant because since the start of the UNAIDS strategy, the targets around stigma and discrimination has been very broad and very difficult to measure, but having a focussed partnership, focusing on stigma and discrimination provides partners a way to work together and collaborate in not only achieving the targets of zero discrimination, but also trying to reflect from the SDG targets...So it's been almost two years since the partnership has established, but it seems like from both the UN level, and from the government level there has been a lack of interest in participating in such partnership. It's very reflective of the government's priorities and lack of courage from UN agencies, including UNAIDS itself to really face the issues and challenges head on.” (Civil society organisation)

“One has to question how influential is the UN at a country setting to get countries to change their minds about many of these issues.” (Individual expert)

COVID-19 is exacerbating stigma, discrimination and human rights violations in many countries

“The police brutality in implementing lockdowns is ... something we are finding in many countries.” (Academia and research)

“Governments are using COVID as cover for cracking down on some of the criminalised marginal of populations. And some of the surveillance measures that some of the governments are thinking about - human rights related issues.” (Donor)

“Most government reluctance to include sex workers in any of their humanitarian responses. Even in Nevada, sex workers are explicitly excluded from COVID emergency responses that are available to people - explicit responses.” (Key population, women or youth network)

“I have been quite taken aback by how we have seen echoes of stigma in COVID that remind us of HIV. I've seen healthcare workers being stigmatised even where they have not been diagnosed, but just because they have interacted with patients with COVID. It's not easy for healthcare workers to integrate back into their communities, or even being shunned by their very families because of contact with COVID.” (Academia and research)

Strategic questions

How to reduce or address discrimination in a world that believes key populations and PLHIV should be shunned or are not deserving of support?

“How do you see the prospects to reduce discrimination and promote integration of people living with HIV to national programmes, in a world with a very toxic language against people who are vulnerable, with the closure of borders and promotion of politics for the exclusion of many segments of population?” (UN Agency)

“How to convince governments that are in denial of not recognising key populations? Or governments that are in their early years of AIDS struggles? and who say homosexuals are an import, even though there have been homosexuals in the country for years. What does it take to convince them?... Governments, to save their image, and sometimes for the electorate, they may not speak of homosexuals or key populations but they should let us provide services and not get in the way. But how do we convince these governments?” (PLHIV network)

“Some of them might not agree or not be interested in human rights but we need to make sure that we can advocate for anti-discrimination on practical purposes. If we only concentrate on the most discriminated and marginalised people in terms of messaging, we’re going to alienate the broader public and politicians. It’s important that we don’t do that because it influences how money flows and how laws and policies are made and without money and the laws and the policy action, I think we can forget it.” (Individual expert)

“How we are going to move forward is to change people’s perceptions of our communities as being worthy human beings of value in our society. And I think we have a long way to go on that. But unless we start focusing on that, just giving us PrEP is not going to solve this issue.” (Key population, women or youth network)

“So we really need a legal policy, governmental reform. If we’re going to change the dynamic, particularly for key populations, why are they key populations? So it’s mostly because of bad laws and policies and practices that keep them in the shadows and that we’re going to have to change if we really want to see, you know, things significantly improve for the most vulnerable people.” (Academia and research)

“We will certainly not reach our targets and we will continue neglecting vulnerable and marginalised people because we are continuing with business as usual. I’m not blaming UNAIDS, they are just the secretariat. When I talk about the leadership of UNAIDS, I mean the big picture: member states, NGOs, co-sponsors.” (PCB member)

“The social cultural plays an important role and those are beyond our control. So as far as the ministry of health is concerned we will try our level best to provide a safe environment so that they feel safe and open when they come to us.” (PCB Member)

What is the role of evidence in the human rights response to HIV?

"We need to be approaching the AIDS response from a scientific point of view, not a moralistic point of view." (Key population, women or youth network)

"The countries that have done well and have listened to the scientific evidence and responded quickly." (Academia and research)

"What evidence do I need to present to get people to actually sit up and take notice and take action around the epidemic that is sweeping through key populations? Because we have lots of evidence." (Key population, women or youth network)

"When faced with honest and credible numbers about how a population is affected, it has shown the ability to be useful to push agendas that might have not otherwise have accelerated. Once that evidence is made visible and presented and brought to bear - it becomes hard to turn away. So painstaking effort to collect data, model it, etc. While investment in data, while it seems secondary to the direct care that people need - it has allowed us to illuminate things that can then be used." (PCB member)

"I think we must take count that the world is full of many more crazies that won't be persuaded by science and evidence. That'll be important for the future of HIV response." (PCB member)

"For the last 20 years I feel that the world was a better place because people know what stupid is, and they can just call it out. But now it seems they wear it as a badge of honour! ... No matter how much access that we are providing people with – because people can access that information – it doesn't correlate with the level of maturity of a society apparently!" (PLHIV network)

What can communities themselves do to reduce stigma and discrimination?

"So the reason that people weren't going to the government clinics, which were free, was that the way that they were treated was as if they weren't human beings, and the stigma and discrimination was huge. And so what they did on World AIDS Day, is a group of sex workers went into one of the government clinics with buckets and soap and they cleaned it! It wasn't very clean (having been there), and they cleaned it and then decorated it. They got some paint and freshly painted it. And the staff in that clinic began to work with them, and from that tiny little bit, relationships changed; sex workers were brought in as volunteers in the clinic, they now have a patient referral system which is really solid, and is trusted by community ... we are not looking at those little things always." (Key population, women or youth network)

What is the role of faith-based organisations in the HIV response?

"Religious should not have a prominent seat in health discussions." (Key population, women or youth network)

“I don't believe we should invite religious leaders to influence them. ... We can have open dialogues with people that don't agree - but hard to do so with people that believe that I am a creature of the devil.” (Key population, women or youth network)

“For a successful outcome, there need to be many more local religious communities that are helpful in reducing stigma than harmful. We'll never get rid of all the harmful ones, but we need enough helpful ones to overwhelm that. And part of being helpful is to realise the need, to treat everybody with dignity and respect, even if they live in a way that doesn't match the way you think God tells us to live. Ten years, we can't expect there to be major changes in belief ... but what they can change is the way they deal with men who have sex with men.” (Civil society organisation)

“It's really important for there to be strong engagement with faith leaders in the process ... part of being a strong, helpful force is to be closely involved in the strategizing.” (Civil society organisation)

“In [interviewee's country], it's the church health places that provide much more friendly services than the government - more friendly and less moralistic than the government. I think that it's that sense of pure compassion and understanding of their view of Christianity, which is more open and less judgemental. Where we see more judgemental groups is with fundamentalist Pentecostal types. The mainline churches provide excellent services. In this age of swinging to the right, it's hard to know how to really change people. But we can't stop.” (Individual expert)

How to adequately measure stigma and discrimination?

“We've had some challenges there with the measurement and as a country, trying to determine who and how stigma should be measured and who should measure it and therefore who should have the resources to undertake those measurements ... So I can't even give a current status report on stigma and discrimination.” (National coordination mechanism)

“How do you even measuring, measuring the indicators for stigma and discrimination reduction and human rights? ... So people would rather go with the numbers where they are able to say, we tested a hundred women, we got 10 HIV positive ones, and seven out of those started on treatment.” (PLHIV network)

“Without any direct targets towards ensuring and concrete action on how do we make sure that stigma and discrimination doesn't happen and if they happen there will be legal and address mechanisms available in place and something that we can actually measure at the country level.” (Civil society organisation)

How to integrate human rights in relation to PLHIV, vulnerable groups and key populations into the health system?

“Instituting laws that criminalise the discrimination of people with HIV or AIDS is important but not enough. Programs to train the people who implement the laws or policies need to be put into place to eliminate discriminatory practices.” (PCB member)

“The right to health is a right. The texts are very beautiful everywhere but the reality is different. We will say that the whole population has the right to health, but it does not happen like that. This human right must therefore be integrated into the health system.”
(PLHIV network)

“In order for HIV to be normalised, we need a complete change in attitudes and break down of human rights barriers. We need investment in public health systems that work for all people and actually work ... We have to invest in social education for health workers. If you could get them to understand the importance of the human rights side, that would possibly filter out into society at large. We do still need to focus very much on health workers.” (Individual expert)

“We also have to raise the awareness of medical personnel. For example, we were working with medical personnel on treatment for sex workers, including trans sex workers, and there was a doctor who was very homophobic ...The system also needs to treat people with respect, and not make treat you differently if you are HIV positive.” (Key population, women or youth network)

Areas of alignment

“In this next strategy we need to be paying attention to the same things, but in different ways.” (Individual expert)

“Sometimes the goals remain unchanged. It's just a different way to get there. Particularly when you're stuck.” (Academia and research)

This section focuses themes where there is high-level alignment and agreement from respondents – aspects of the current UNAIDS strategy that need to be maintained, strengthened or invigorated. These include the following:

1. Take existing and emerging realities into account;
2. Address structural drivers of inequality;
3. Focus on both the biomedical and human rights;
4. Place PLHIV and communities at the centre of the response;
5. Collaborate and partner;
6. The response must be granular and context specific
7. Mobilise exceptional political leadership; and
8. The AIDS response needs to be properly financed

Although there is high-level alignment on these eight key strategic areas, the sections below aim to capture some of the nuances and differences in perspectives.

1. Take existing and emerging realities into account

Overview

COVID-19 is currently taking centre stage

“Right now the biggest reality whether we want it or not is COVID. So the new strategy should really look at the potential impact of COVID and how we can mitigate that impact. Because if we don't, I see a lot of reversal of the gains that we got at a very painful cost over many years.” (Academia and research)

“COVID can really spiral out of control to an extent that really damages momentum for progress towards the end of AIDS, by destroying economies, jobs being lost and people not being able to access care.” (Academia and research)

“One can see that if there is a societal chaos related to things like COVID, whether it's driven by for example, reversals in economic gains, it can fuel reversals in stigma.” (Academia and research)

“If we are not prepared for another pandemic we will have the same panic as COVID, HIV will certainly go down the drain because we don't have resources for any other disease.” (Individual expert)

There are other existing and emerging trends that need attention

“What we are seeing with COVID is the temptation for nations to close their borders, and put travel restrictions. And so I think one of the scenarios from hell is for the reverse of globalisation to happen, for nations to become very inward looking and therefore instead of regional approaches, you find fragmented approaches that do not serve the broader development agenda, and in turn do not serve the development of the health sector.” (Academia and research)

“I think what would make it successful is it should address emerging realities. And right now the biggest reality whether we want it or not is COVID. So the new strategy should really look at the potential impact of COVID and how we can mitigate that impact. Because if we don't, I see a lot of reversal of the gains that we got at a very painful cost over many years. And yet, this is something that has unfolded just four months ago. So adaptability to emerging situations is very important.” (Academia and research)

“The rise of the right and religious fundamentalism is a huge problem in terms of our understanding society, how it works, making life fair for all, giving everyone the same opportunities ... It's a real danger what we're going through politically. There's huge uncertainty about how societies will respond to any issue.” (Individual expert)

“I do think that a large part of the world that's falling under these strong men is not interested in that, because a strong autonomous civil society that helps you with health also

challenges you on human rights and other issues. We're seeing people trying to close this down.” (PCB member)

“I think human rights are more on the agenda now ... with the global anti-racism and Black Lives Matter momentum that seems to be gathering.” (PCB member)

“We are beginning to see the impact of climate change ... in Uganda's case, we have seen a number of things ... there's been flooding, torrential, rain falls leading to displacement of people and destruction of road infrastructure. And in my mind, it creates a lot of uncertainty.” (Academia and research)

Challenges

HIV is no longer a priority

“When I look at the priorities of the WHO in general, I see that HIV/AIDS no longer has the same level of priority. It is true that there have been advances, but it is too early to forget about HIV and AIDS. Will we lose all of our efforts because there are competing diseases and priorities?” (PLHIV network)

“How to keep the fight against AIDS in the agenda for the long term... there are so many topics now in the agenda that it is so difficult really to maintain the attention of governments and the public opinion.” (UN agency)

“It seems that HIV and AIDS has decreased as a priority on the global agenda including financially. This is a concern.” (PCB member)

Strategic questions

How to put AIDS back on the agenda in a time of competing demands and interests?

“HIV/AIDS has had a special place in the medical world and among leaders, in relation to other things that may kill more people.” (Academia and research)

“The challenge for UNAIDS is going to be how to put AIDS back on the agenda?” (Individual expert)

“UNAIDS will need to be targeted and focused, showing the world that you can't take your eyes off HIV just yet.” (Academia and research)

“We've had a special place for the last four decades. But to think about how to work in this new world. That means we need to keep on the message, we need to work more smartly, be more efficient, show results.” (Academia and research)

“HIV, it's not the only health challenge that we have. It's not the only social challenge we have. So we've got to figure out how do we balance our responses in one crisis without exacerbating and reversing gains we've made in other health challenges facing us.”
(Academia and research)

“When you are talking about malaria, it's completely different than talking about AIDS and in order to advocate for AIDS, and it's a talk for issues about issues that you don't need to talk to when you were talking about malaria or other disease. So that kind of exceptionality needs to be revamped in some way.” (Civil society organisation)

“Whether its COVID or global warming, HIV as an issue needs to find its place in the world.” (Professional society/association)

“I see a lot in civil society actually, maybe more than in UNAIDS, that's just bleating about how important HIV is and bleating about how we should have more money like we used to in the olden days and thinking that everyone else in global health and including the women's movement are the enemy. That's a recipe for disaster. It's a recipe for being the sad kids who stands in the corner and no one pays any attention.” (PCB Member)

How to use COVID-19 to build a more robust and flexible strategy?

“It's a very opportune moment for us to be designing this strategy, exactly knowing how hard we will be in the field, because could you imagine if we closed this strategy last year and then they have now COVID and everything, it would be a mess.” (Civil society organisation)

“We must be mindful of how COVID will impact on all of our strategy development.”
(Donor)

“What impact COVID will have on HIV in terms of how we position HIV in the future? Many of us have a fear that HIV will go down the agenda to the point where it will emerge as a global pandemic if we lose sight of it.” (Key population, women or youth network)

“I've learned that strategy has got to be almost opportunistic and seizing the moment. It's good to have five year plans, and long-term plans, but when COVID, for example, emerges, your strategy should adapt to that new challenge and even get momentum from it if we can.” (Academia and research)

How to leverage the experiences from the HIV response to build preparedness for future pandemics?

“HIV AIDS was the world's last pandemic.” (Donor)

“Having weathered the HIV pandemic, and now COVID - what can we learn to prepare for the next one? Will we have a time of reflection around our preparedness, how do we plug our gaps and strengthen systems instead of inviting the next crisis?” (Academia and research)

“Preparedness is one of the first things that comes to mind. What we’re understanding from COVID is this is not going to be the last... From the standpoint of HIV, what’s the additional preparedness strategy to protect those who by definition have an underlying condition? There should be dedicated resources for preparedness. This isn’t a new idea or a new topic.” (Civil society organisation)

“The learnings from the activism of the key populations and the learnings from UNAIDS as a joint programme in itself in how to respond to present and future pandemics, including pandemic emergencies. There’s a lot of learning out there.” (Civil society organisation)

2. Address structural drivers of inequality

Overview

HIV cannot be effectively addressed without looking at the social drivers of health

“Whether you benefit from the fruits of scientific progress is absolutely a function of your access to a minimum standard of living, your access to nutrition, freedom from violence, whether the full range of your civil, social, political, economic, cultural rights are respected - its going to be what determines whether you can benefit from the technological breakthroughs.” (Donor)

“Access to health services is not happening where societies have different type of disparities depending on gender, economy, social status.” (PLHIV network)

“The advances have not been uniform. We still see both in terms of access to treatment, as well as access to prevention, disparities. And that's the next challenge ahead of us is how do we overcome these disparities? We have to overcome these disparities if we want everybody to have access to prevention and treatment and to live well and have a productive life with HIV.” (Academia and research)

“Our strategy was to have more people tested and on treatment, but there wasn't as much emphasis on inequalities and barriers of how people can access the testing and the treatment. As a result of not addressing social issues, inequalities and barriers, you can't succeed at eliminating new infections and deaths.” (Civil society organisation)

“I think within that global health architecture there is a need to rethink ... how do we perceive health, because at the moment I keep on feeling that health is actually being traded within the economic argument, as a tool to achieve economic prosperity, but that is exactly where the problem is because for groups whose size cannot make an economic argument they will be just left behind.” (PLHIV network)

Challenges

HIV has become an issue of the poor

“I think that one of the reason that there has been such research in HIV and such strides because in the early stages it was people in the West who were infected as much as anywhere else and who led the fight. They had greater access to make the arguments to government about this kind of work. As time goes by and it becomes more a disease of the developing world, you are losing that kind of advocacy as well.” (Individual expert)

“As the most affluent members have moved on, they are not as driven to be part of the advocacy because their needs are met. And now the most impoverished disenfranchised communities are left to continue to try and make do with less.” (Civil society organisation)

“To a degree there is a complacency that has crept in around HIV as we’ve got treatment and people no longer need to be as angry and on the street.” (Key population, women or youth network)

“HIV, TB, and Malaria, are all in their own way residual pandemics. They were once pandemics. They’ve been contained in the richer parts of the world in the way that the richer parts of the world no longer see them as a health and security risk, but they’re still killing lots of people in the poorer parts and in marginalised communities.” (Donor)

Racial, gender and economic inequalities intersect

“HIV rates amongst people of colour in the USA are as bad as they are in the poorest countries in the world.” (Donor)

“Black women get decimated even before they reach the age of maturity... the vulnerability of adolescent girls and young women is what puts women, and particularly young black women on a completely different trajectory from boys and men, and that is one of dependence and vicious cycles of dependency on men because they don't finish high school. And so the employment opportunities are very limited and HIV within that and teen pregnancies all come together.” (Academia and research)

“There is a need to appreciate and work with cultural differences and masculine cultural norms, intersections between gender inequality as well as violence against women especially where women do not have a voice.” (PCB member)

“I can see there is ... increased level of violence in the whole region, violence at the different levels, of political level, at the community level, violence affecting a woman, sexual violence or gender based violence, but also affecting many minority groups.” UN Agency)

“It is difficult to focus on issues of sexual and reproductive health when the primary issues people are grappling with is poverty, and the ability to access food.” (PCB member)

“In Russia, Ukraine, rich countries there are already a number of people who buy ARV treatment, because they want better treatment or secure anonymity in treatment. It makes diversity in services, one person will get treatment for free and be registered with all those risks, whilst another can consult a doctor and get their own medicine.” (Key population, women or youth network)

COVID-19 is exposing these fault lines further

“These issues of rights, socioeconomic vulnerabilities, and vulnerability in terms of who survives and who dies when exposed. We've seen the data from the U.S. particularly, where, again, it's blacks who bear the brunt of it, it's women, younger people.” (Academia and research)

“COVID dramatizes the importance to the social determinants of health in order for people's right to health to be realised. In other words, one's right to health is a function of economic

status, access to livelihood, to food and nutrition and clean water, gender, criminalised in society - all of that has been lain out so starkly.” (Donor)

“Millions and millions of people will enter in extreme poverty. So when you have to choose between eating, and choosing about your sexuality security life, what do you take? You’re just eating, right? So we will have sex without protection. We will do whatever we want to do to survive.” (Civil society organisation)

Strategic questions

How to meaningfully deal with the structural drivers of inequality?

“How do you address these inequities? It's not by dealing with it as a ... homogenous global problem, but dealing with it at a very local level, taking some of these disparities and inequities into account. And I think that ties in much better with the SDG goals that are linked to these HIV targets being met, because it talks about integrated strategies because that's the other piece.” (Academia and research)

“I think we need more attention to racial issues because I think that in the old strategy, we would talk in the lot about gender, which is excellent. We need to continue doing so, but we need to take a look on racial as well. You know, more strategic actions related to specific populations that are left behind because of racial issues.” (Civil society organisation)

“We're having that painful discussion about the lack of diversity within our own organisation. We're primarily white and for an epidemic that primarily affects people of colour in the US and around the globe. And it's time that we need to be held accountable for that on all levels. And I think that's the only way that we're going to see the people at the table who are most impacted by these injustices, who have really the drive to go out there and push back and, and rock the status quo.” (Civil society organisation)

How can secondary education, including sexuality education be strengthened?

“I can tell you, a lot of young people in Nigeria, if you ask them how is HIV transmitted or you ask them the basic knowledge about protection etc., a lot of the young people don't even know, because we don't have those school education programmes that used to exist in the past, we don't have the resourcing that has gone into prevention programmes that we used to have in the past. In the 80s and 90s you would go round and you would see a lot of billboards, you see TV, the radio jingles about HIV etc., but when was the last time I saw anything related to that?!” (PCB member)

“Invest more in those who are more vulnerable, to promote more the inclusion, invest more in education, to support more the more isolated areas of the countries – really to work together towards the reduction of inequalities.” (UN Agency)

“The strengths that got the HIV response where it is, are the strengths of coalescing everybody outside of the health sector together in order to get the best indicators for health,

make a significant difference. This is a place where UNAIDS needs to think, what does having had a multi-sector approach, what does it mean – education being one sector for instance.” (National coordination mechanism)

“In the developing world, populations are going to be increasingly young, so we have to invest far more in education to children, and opportunities generally.” (Individual expert)

“I do think education in schools is really important. Obviously keeping girls in schools is really important too. The greater education a woman has the far less likely she is to get HIV.” (Individual expert)

“Look at the curriculum of these schools and try to find what kind of targets are in gender education. Or if you have sex education it is hardly ever mentioned as a target during an education trajectory.” (Private sector)

“The next global strategy... comprehensive sexuality education, and when I talk about sexuality education, also effective sexuality and effectiveness education – it is not only about sex, it is about also partnership and love.” (Multilateral/ Intergovernmental organisation)

“Make sure that there are proper school education programmes around HIV, human sexuality, gender violence – all of these systemic issues that need to be sorted out.” (Individual expert)

“There are also systemic issues, like keeping girls – and boys – but girls in particular in school until they are 18, so universal primary and secondary education is a major, major HIV prevention intervention. So those systemic things work, and could be major constraints if they are not funded.” (Individual expert)

How to use the COVID moment to transform health systems?

“Looking at the world the way it is, with COVID, also with George Floyd, there is a real recognition that the whole system is broken, the health systems are broken and they're inadequate.” (Key population, women or youth network)

“Look what’s going on with the Black Lives Matter... How is UNAIDS connected with that kind of working/thinking the causes and issues?” (Individual expert)

“We've never had the opportunity that we have right now, caused by the COVID crisis ... for citizens to demand a different approach going forward. And this is a different approach domestically in terms of investment in people, investment in social services, investment in social protection investment in a more just, ... this is in the US especially, reflected even more in the protest movement that that's underway right now, where it's looking, not just in general terms, but looking at particularly those that are historically disadvantaged or actively repressed by systems and by governments and by people to demand a different approach and to completely rethink things... we've never had an opportunity since the formation of the UN for that... it's so massive that it's hard to conceptualise, but it's everything from reforming police systems to looking at the things that we need for climate

change, like complete restructuring of economies away from fossil fuels and all these types of things.” (UN Agency)

“Does any country seize on the transformational opportunity to respond to COVID-19 by strengthening its social safety nets and redoubling its efforts on delivering on universal access and universal health care?” (Donor)

“Pre-Covid, you could already see how difficult it has been during the period of focus on Universal Health Care. Speaking to any ministers, you can see the issues they’re having with allocating the funds. They really are in a different mind frame now, which is: How do we provide health care to a much bigger part of our population?” (Civil society organisation)

“I love the idea except that it is difficult to say what it is... I am a bit afraid that if you lose the focus on HIV and the programmatic approach with real target setting and a time line and developing it, it is going to be drowned in all the other issues.” (Private sector)

3. Focus on both biomedical advances and human rights

Overview

Because HIV touches on the heart of morality and social and cultural norms, it cannot only be dealt with biomedically. At the same time, biomedical solutions are vital.

“The key to what has worked is that it's not just a political and a human rights response, but it's also a medical response. We haven't lost track of the reality that what people need and demand is access to health services. And so while we work on law reform and reducing stigma and changing structures, the AIDS response has also really worked on scaling up HIV treatment and getting people access to PrEP and figuring out how to create new tools.”
(Academia and research)

This dual response has saved lives

“The fact that I am alive and well speaks a lot to science and advocacy and human rights.”
(Professional society/association)

The strategic response needs to maintain this dual focus

“The necessary positioning for UNAIDS is to continue to walk a line where what it does is it focuses on two things: one it boldly and clearly articulates the human rights vision and makes that a key part of what it does. And I think the human rights division is not just about: ‘don't lock people up, don't criminalise them’. It's also about: “don't prevent people from getting access to patented medicines. It's also about realising the right to health by sufficiently funding your health system? There's all of these messages that UNAIDS needs to be behind and needs to demand. But it also must be a premier hub for scientific work on HIV. And that provides the world with data and analysis about how you fight the AIDS pandemic in a very credible way. And if UNAIDS loses that latter part, which it has and needs to strengthen, if it doesn't focus on strengthening that part, it will be crushed.”
(Academia and research)

“UNAIDS has two very important roles. First is the voice role, the advocacy role, the scientific activism, which is the screaming and shouting and aligning itself to all other advocacy groups and activism groups to demand, change, to demand funding, to demand action. It's one of the few UN agencies that is allowed to do that ... The second is the collection and dissemination on data and progress around agreed targets... because that holds countries accountable, shames them to some extent and reminds the world that we have a long way to go.” (Individual expert)

“When talking about the interaction between human rights, prevention, and treatment, it is important to keep in mind that human rights are important. In my country the constitution is beautiful. It is a constitution that guarantees rights. But it's just words. In reality it doesn't happen.” (Key population, women or youth network)

Challenges

Over-medicalisation

“First is over-medicalising the epidemic. We’ve swung the pendulum too much on the other side. Before we got ARVs we were focused on behaviour.” (Individual expert)

“Because you are dealing with drugs and medicines, things are being very medicalised. We need to get out of that silo that HIV is a medical problem and go back to addressing the societal things.” (Private sector)

“We need a response that’s not just male circumcision and pills ... Even from a biomedical perspective there are big structural issues that we have to confront otherwise we’ll hit the same kind of blocks. For example, the health system is fragmented and so much money going into public health is actually invested into the private sector.” (Civil society organisation)

Strategic questions

What is UNAIDS’ role in this dual response?

“It is important to recall that the primary role of UNAIDS is as a moral authority... If UNAIDS goes back to playing a normative and technical role, it would miss the point... UNAIDS should be doing political advocacy, political advocacy, political advocacy. Do that first and the rest will follow.” (PCB member)

“The country must be clear on its own strategic plan of action, then UNAIDS can provide the technical support.” (PCB member)

“UNAIDS shouldn’t become an organisation that just focuses on community partnerships, there’s an important leadership role to look at issues of IP and macro factors that deal with how we address poverty, user fees, etc. There are times when there hasn’t been enough on the side of staking out those bigger issues, IP in particular. Potentially, there’s a risk of being seen as incoherent if you can’t explain how you work at both of those levels. So you need a framing: Human rights is one of the ways in which you explain it. You can make human rights-based arguments on IP reform as well as micro-issues.” (Individual expert)

“The other thing that was important in the past years ... there were more conversations around the legal environment... in order for us to respond to the human rights and key populations violations that work was, somehow dropped in the past years with the UNAIDS. It needs to come stronger for this time now.” (Civil society organisation)

“UNAIDS could focus on supporting local civil society to overcome the more difficult aspects like legal impediments, helping to integrate programmes and strengthening civil society and working with Global Fund, to complement what WHO is doing.” (Academia and research)

4. Focus on people living with HIV and community-led responses

Overview

The success of the HIV response over the past decades rests on community mobilisation

“I think we have achieved a lot and we have to a great extent achieved it through exceptionalism, by not accepting that it was just like any poverty-related disease, that it would be allowed to just continue untreated in the poor countries. So we reacted early on. There was a real sense of solidarity, and community mobilisation was central ... I will always argue that it is not because somebody showed the economic feasibility of it that treatment got rolled out the way it did. That came afterwards.” (Civil society organisation)

“There wasn't so much political attention at the beginning of HIV. ... but with enough community mobilisation and calling people out, that's what really built the HIV response.” (Key population, women or youth network)

It showed the importance of bringing PLHIV, and key populations and communities affected by HIV into all aspects of design, decision-making and delivery

“Doctors don't know the disease as well as those who live with it, especially the social and cultural dimensions and the challenges of compliance.” (PCB member)

“In many countries, eliminating discrimination is the work of people living with HIV. You can't perceive discrimination unless you are living it. Sharing experiences of discrimination requires a lot of effort, to be open about your status.” (PLHIV network)

“Who better knows their response than the people affected by the disease, so bringing the communities into the conversation, not as an afterthought, but as an integral designer, planner implementer was very, very important in the responses in the past.” (Key population, women or youth network)

“Activists fought their way to the table and made remarkable changes in how all sorts of governance things happen. And that includes the standard at this point that you don't run HIV clinical trials without including people living with HIV and communities in the governance of those, to the Global Fund, where there's representation of communities and there's political power there, there's voting representation on the Global Fund board of communities and NGOs. And that's remarkable because if you look across global funding structures, there's actually not another one in the world that has real voting membership for communities affected by the question, and for NGOs.” (Academia and research)

Community led organisations and responses play a crucial role in better healthcare and HIV responses

“The strength of delivery by community organisations is that key populations are more comfortable coming to community structures than to hospital structures.” (PLHIV network)

“Peer to peer counselling is more effective than that provided by doctors and health staff. People are more likely to listen to their peers.” (National coordination mechanism)

“HIV taught us the power of civil society to contribute to better health care for people. It helps to overcome stigma, unfriendliness, but also because it is pragmatic and on the ground.” (Academia and research)

“A number of us have developed really solid services that respond to the needs of our community in a way that our community feels comfortable with.” (Key population, women or youth network)

“We provide peer to peer counselling online. We have a lot of requests from young girls and women. They don’t speak with doctors or parents about their health. They speak with friends, but they don’t have good quality information. So now we have 15 teams in multiple countries including Russia.” (Key population, women or youth network)

Civil society involvement is essential in ensuring that the voices and rights of marginal groups are not side-lined

“The need for civil society is essential, particularly in countries that do not foster the involvement of NGOs or even countries that censor civil society involvement. These countries tend to have the weakest responses.” (Key population, women or youth network)

“We see in developed countries, civil society have had a more prominent role in shaping the AIDS response than in developing countries. In these less equal contexts, civil society has been relatively weak, and this becomes much more important.” (Key population, women or youth network)

“By definition of democracy, that means that the government represents the majority of the people – which is why civil society and communities are important because they bring the voices of the minorities and those who are marginalised and out of the mainstream society basically.” (PLHIV network)

Civil society can say things that other actors may not be able to

“As the community, we have the role to unblock the situation and say or translate what an agent of the WHO or UNAIDS want to say, but cannot say. This is where our complementarity lies; our role is to report where things don't work.” (PLHIV network)

“The role of civil society for me becomes critical, not just to come to conferences and be part of a panel – with due respect – but as a visionary vehicle for shaping and keeping sharp the response, and also as the voice to speak truth to power in ways that only civil society can do.” (Civil society organisation)

The next strategy will need to continue to put PLHIV and communities most affected by HIV at the centre of any response, not as recipients and beneficiaries but as equal partners

“A disease like HIV must be met with a community based approach beyond traditional health structures and facilities. Not only for activism and advocacy, but also for the delivery of services and treatment.” (Academia and research)

“Strengthen the active leadership and role of civil society organisations, especially communities of people living with the disease. They are the strongest mover of everything.” (PCB member)

The strategy needs to focus on specific communities where HIV risk and prevalence is greatest, namely vulnerable and marginalised communities

“I think they should have community-led responses should have a specific dedicated chapter in this strategy and to be also followed by funding allocation and structure. Because then it could also make the difference among the population that were not yet reached by the current strategy.” (Civil society organisation)

“We should put 80% of our efforts on vulnerable and marginalised people. If you can change that situation, you can change everything. Put them as the first mile of the strategy.” (PCB member)

Challenges

Communities and community-led organisations are not treated as equal partners. They are excluded from decision-making.

“I am hoping that this strategy be a community strategy – that is the first thing – meaning that there is a boldness to say ‘Yes we hear you government and we understand, ... but we are also hearing communities who are most affected and these are some of the things that they are saying and we want some of these things to be reflected in this strategy.’” (Key population, women or youth network)

“We see now that the round tables are just with institutions, and the social sector organisations are left out, when it is the social organisations that are doing the work of the state. The social organisations are doing the work of prevention, health promotion. But we aren't considered or taken into account to contribute to the development of health policies which are going to be specifically for the key populations.” (Key population, women or youth network)

Their experience, knowledge and insights are not taken seriously

“We talk about the hospital structure by saying ‘the experts and professional’, it is as if what the community does is not professional. But these people work in the logic of the community world, and they are qualified. We often contrast community work with the work of professionals as if we had no experience.” (PLHIV network)

Involvement and engagement of civil society has decreased and weakened over time

“We see the gradual alienation of civil society for the last 6-7 years. In the field, there isn’t a sense of meaningful involvement by the key populations - people are treated as clients and not as partners. Need to rebuild confidence with civil society.” (Expert individual)

“The technicalisation of the response was allowed to slip in, and there wasn’t the same kind of unitedness and focus, and it became about AIDS conferences and positions and UNAIDS technical task teams ... and civil society being co-opted into a framework of the response where I felt at times civil society lost its independence. And it is a much more divided movement and very fractured.” (Civil society organisation)

“The feminist movement ... moved on and I think what was left is a big space for vision and activism, that is not occupied as dynamically as before.” (Civil society organisation)

Funding for civil society has decreased

“In the past, there were some forums for policy making that included the key populations, but now there are not resources there to support this work. There are not resources to enable us to be involved, and all of the policy conversations happen in the Capital. It is costly and time consuming for us to get there. And sometimes we are given almost no notice and can't make the long journey in time.” (Key population, women or youth network)

“We are beginning to take our finger off that pulse, and we are decreasing our resources to civil society.” (Academia and research)

“We have a lot of data and evidence that shows us that when you invest in communities, you get better and greater results and outcomes with limited resources. But then every other time ... let it be any funding mechanism, there's always struggle to make resources move to focusing on community programmes and activities. If you have a two-day meeting or a one-day meeting, you spend probably 80% hearing communities, communities, community engagement is good. But when it comes to programming for that and putting the resources there, it will be like 1%. Then the question is what happened in between there?” (PLHIV network)

Funding that is available for civic responses is often compromised funding

“The funding landscape has changed dramatically, for organisations working on HIV and the funders that remain rarely are interested in truly radical systems change.” (Civil society organisation)

“For the first time perhaps our history at [advocacy organisation] ... our HIV project is primarily funded by pharmaceutical companies... And so that level of control over the voices that are supposed to be independent advocate voices, is challenging and scary.” (Civil society organisation)

“Coming up with those sustainable models for the long-term that doesn't ultimately compromise our voices, is challenging and ultimately ends up in also being a patchwork of

funding, which also becomes burdensome in another way, because each funder has their own criteria and objectives and reporting and at some point, how do we get away from the administrative work to actually do the meaningful programmatic work?” (Civil society organisation)

There are tensions and struggles among different civil society and community movements

“We talk of solidarity, we talk of safe spaces, we talk of movement building, but the conflicts that I find within the networks, the civil society movements in the response to HIV... There is still violence within the movements, within the workplaces. There is violence, physically, emotionally and financially.” (Key population, women or youth network)

Apart from key populations, other priority populations are underserved by the HIV response

“There are more displaced people right now in the world than there have ever been almost 80 million people and refugees are internally displaced. And many of them are in places where there's high burdens of HIV.” (Academia and research)

“Without the involvement of prisons in our efforts against HIV, it would be very hard to achieve our targets. The Ministry of Health is usually not interested in prisons. You have to increase integration between the ministries of Justice and Health.” (PCB member)

“Let me speak from a SADC perspective, Southern African region perspective and someone working with adolescents. In this region, what's clear to us is a massive failure to find solutions for adolescents.” (PCB member)

“We are behind in addressing paediatric populations. Despite the efforts made by UNAIDS, we can see that it's not advancing ... we're seeing that there are children who are infected and not treated. Just because children can't yell like adults, they aren't treated.” (PLHIV network)

“We have struggled in Uganda to make sure that men match women, when it comes to access to care. We know for example, that across Africa and in Uganda, almost two thirds are women, tells you that there might be a problem with the men. So we have struggled to bring them into testing and also to retain men in care.” (Academia and research)

Strategic questions

Can we really reach the last 10%?

“Can we really reach that 10% of difficult to reach people with HIV who are being left behind – can we do it? Have we got the right tools, have we got the right actors, have we got the right political commitment to achieve that?” (Private sector)

How to ensure that PLHIV and communities are genuine partners in this strategy process?

“The first step is to listen to the key populations and what they need, and then to look for strategies that work with government, international organisations, and the key populations, and find the best answers to HIV AIDS.” (Key population, women or youth network)

“The AIDS response has really championed the participation of the communities from the very onset of the epidemic that has to continue.” (Civil society organisation)

“UNAIDS could be reasonably accused of tokenism in the past. And I think that is really important to stop. I think the engagement with different populations has to be authentic, has to be credible and it can’t be just to tick a box for saying that there has been a consultation.” (Private sector)

How does the next strategy balance the focus on key populations with other underserved populations?

“The first thing is strong prioritisation of the vulnerable and marginalised groups for prevention, treatment and care. ... If you cannot reach these groups, you can never hit the targets. So instead of trying to cover the general population we must prioritise these groups. Otherwise limited resources will be drained.” (PCB member)

“The key populations framing has distanced the rest of civil society from the response and made it about technical things. But we need civil society to be able to make radical statements. Not to attend more conferences the role of civil society but as a visionary vehicle for keeping sharp a response and to speak truth to power in ways that only civil society is best placed to do.” (Civil society organisation)

“I was always curious about this framing of key populations ... because I think what that did then was kind of distanced the rest of civil society from the response and made it about technical things.” (Civil society organisation)

“What’s the consequence of carving out a narrow look at [certain] key populations and saying: these are the ones we’ll invite to our meetings, these are the ones we’ll ask countries to address? There are other populations that are neglected: migrant populations, people with disabilities, prison populations.” (Individual expert)

“I’ve had conversations with people at UNAIDS about neglected populations. The response is: ‘the information isn’t good so we can’t really do anything’. Which shows a lack of leadership in dealing with that. Or I hear: ‘How many populations can we realistically address?’” (Individual expert)

“From a process point of view, I think the voice of young people and the voice of men needs to be stronger, not men purely in the sense of men who have sex with men, but men in general needs to be present in that strategy. But I think we need to hear how men believe that they can contribute more to the prevention piece, the stigma, this discrimination piece, the treatment pieces of the response, whether it’s through their own strategies or

supporting national responses, supporting women, supporting families.” (Key population, women or youth network)

“Teenagers can create a new world with new rules and no HIV. To be able to exercise authority in the world, adolescents need to be able to make informed decisions. And to make informed decisions, they need access to good information.” (Key population, women or youth network)

How to change mind-sets around medical professionals as “experts” of the HIV response?

“There is something that happens with especially women living with HIV, with the experiences that we have. When they say this is what is happening with my body or my experiences in the community, then they are called anecdotes. I’m saying, if I’m telling you my story, my story is data. It should be taken as that. If you are the one who is able to write and I’m able to talk, because there are so many women rich in a lot of information that will help the country, that will help the response. Why are they not recognised? Why are they on the margins?” (Key population, women or youth network)

“People in communities, NGO service providers, people in government should all have a role to play in setting research questions. And they should all have access to the same data and be using the same evidence.” (PLHIV network)

“You need a mixed body for research: scientists and community members who can identify relevant topics for research. Usually donors set the research agenda. In a lot of situations, the research questions are selected for the comfort of the authorities, but are unrealistic in their portrayal of communities and patients. We need community-based research.” (PLHIV network)

How to value and credit the work of the community sector?

“It is finally time to valorise work by the community sector, which is done by dedicated people, or people who are infected. That is the reason why results from the community sector are different from the public sector. Community organisations use a third of the budget that public and private structures are using and produce better results. But all that is not valued and documented and it is frustrating. It is high time to give space and enhance the community and that we agree to give credit where it is due so that we can see that we are complementary.” (PLHIV network)

“We, the community sector, are doing what the state should be doing to accompany people with HIV.” (Key population, women or youth network)

“Communities need to be paid attention to in terms of the work they do and the contribution they make to the response and they need to be resourced. This needs to be emphasised. Funding and development partners need to acknowledge and respect and work with our diversity in terms of voices and identities and not compel us to speak with one voice.” (Key population, women or youth network)

“Community health workers is an area that we need to give greater importance to. We need to recognise that community health workers are going to need to be rewarded somehow. You can’t expect everyone to do voluntary labour all of the time. While it has financial implications, it’s still much cheaper than alternative methods and more effective too.” (Individual expert)

How to adequately strengthen community organisations?

“When I talk about strengthening community organisations, I’m not just talking about money. I’m also talking about capacity building and technical support.” (Key population, women or youth network)

“I want to pilot social contracting (community contracting) ... Other neighbouring countries in the region ... have started, working with peer groups and are achieving good results. For that, I need technical assistance. But I have no idea how to pilot it here. I would like to request UNAIDS or other technical agencies to provide technical assistance and funding. We also need capacity building, mentoring and coaching for local community groups to manage these programmes and finances.” (National coordination mechanism)

“For me the question of civil society is not from the lens that says ‘what can UNAIDS do to support civil society?’ but ‘what is the role of civil society beyond the UN system?’ ... I am hoping that part of this process is really going to grapple with the fact that the kind of approach to civil society has blunted the civil society input. And so a conversation with civil society is not just those who are considered immediately relevant to HIV and AIDS, but civil societies that are working on issues like public health and having conversations about what does reimagining public health based on what we are learning about COVID, which is not different from what we learnt about the AIDS epidemic even though those two things are different. Because we keep coming back to the same lessons about the issue of inequality, and the systemic issues continue to confront us and the existing weaknesses of our health care systems, the weaknesses of the capacity of our states to actually lead, and then of course the kind of unclear position of communities and civil societies is haunting us in the same way, or in similar ways. So I think those are some of the things to think about as lenses to a more transformative and ambitious global response to the epidemic.” (Civil society organisation)

How do social movements build solidarity?

“So the HIV/AIDS epidemic and people who work in this field, they need to fully understand that now they have to be united more than ever before, so that we don’t allow governments to stop on HIV to fight Covid-19 - because we don’t want to go back. We are in a place where going back is not acceptable.” (PLHIV network)

“I think the only way lies in integration with the other movements, for social justice and racial justice, gender equality. That’s not going to be easy, but if we don’t manage it, it will be very difficult to sustain the response.” (Civil society organisation)

How to adequately measure community-delivered services?

“We have a target of at least 30% of services delivered by the communities themselves. Until now, we don’t even have a way of measuring this. This target started in 2016 but if you can’t measure, you cannot change. We have a taskforce to work on this, but they’re taking so much time.” (PCB Member)

“We should bring in the civil society organisation and get them involved for example. Some are not making a difference, but there are good ones. For CSOs you should have them in a performance framework. You should spend more on people that create results, not just work with a lot of organisations.” (Private sector)

What is the role of UNAIDS in supporting and engaging communities?

“In all honesty, at country level, the UN country offices are not always playing a good role there. They see us as too difficult, too controversial, as they will lose favour with government. The Government will stop listening to them on more important things if they challenge them on our situations. Although I know what big an ask it is.” (Key population, women or youth network)

“It never felt like UNAIDS could be consistently relied upon, and if anything, the examples where activists felt let down, or wasn’t the political courage to stand with civil society - these cases seemed to outnumber of the positive examples.” (Donor)

“Acknowledgement and involvement and the meaningful engagement of communities in health responses has been the flagship of UNAIDS, and UNAIDS should continue to champion that.” (Civil society organisation)

“UN has quite an important position of the third side in these discussions between government and civil society, Sometimes UN can say things that Civil Society cannot say. UN helps to understand and operationalize and put this work in the right words and right consequences as a project and activity plan... UNAIDS never stood on the side of governments or community, they tried to keep a mediation role.” (Key population, women or youth network)

“I think the cooperation with civil society, UNAIDS offices, regional and national offices with the community that they work with, the contact they have I think this is very important.” (Multilateral/ Intergovernmental organisation)

“What people say in Geneva and what happens in a mining village, the discourse is not percolating down. It's not only the intentions of the people higher up that's going to change the situation. It has really to be brought to communities by everyone involved.” (Private sector)

“We have been protesting and UNAIDS has been our backbone and serves as a mediator and tell the government this is what they want, can you do it? UNAIDS ... may not have the money but they are an influential group that can push. They can talk to the president and

UNAIDS can do that for them. That's why we do not take them for granted.” (PLHIV network)

“I really wonder why UNAIDS have lost the great partnership they had with civil society.” (Individual expert)

“I'm not sure that we've [UNAIDS] significantly protected or forwarded to the civil society space or even perhaps the human rights space in countries where duty bearers went, screw you. We don't like this. We don't like these people. We don't like the freedom. We don't like the NGOs. We're seeing countries Philippines, Russia, Kenya, others, Eastern Europe, closing down the NGOs closing down that space. Because the UN is a collegial member, state system we found no way to punish them, or sanction them that's made any difference.” (PCB Member)

“If UNAIDS can champion to member States, together with key populations organisations, that community based responses are not just an added value, they're not just an afterthought but an integral part of the design of an AIDS response in the country, from making sure that they participate in the development of the programmes and policies, but most importantly, in having a voice by making them part of surveys ... That is going to be very difficult, given that in some countries civil society spaces and civic spaces have been closing, but if UNAIDS can be very firm in terms of making that mandatory, making that integral and important to the process, then I think we can actually move forward in making sure the demands of the communities will be present and will be prioritised.” (Civil society organisation)

“One strategy of working in the countries is to first meet with the people of the countries with HIV and civil society groups. In some countries this approach isn't well appreciated, including in EU. The advantage is that way, you will hear the real issues from the people and maybe it depends on the country, but you can be their voice, their megaphone.” (Individual expert)

How to use the COVID moment to promote the role of community-led responses and organisations in health systems strengthening?

“Covid-19 will give us a real opportunity to create the space to talk about community-led programmes and prevention.” (Civil society organisation)

“For example, during COVID, it is the community organisations that have responded to the needs of key populations. In the big cities there has been some support for these populations, but outside of the centre, there is little support, and so it is the community organisations that are filling the gap.” (Key population, women or youth network)

“COVID raises some things quite starkly: That governments which are more oriented to ensuring social support systems (formal welfare systems or community-based support) have huge advantages, in terms of health care and in terms of rebounding economically.” (Individual expert)

5. Collaborate and partner

Overview

Multi-sectorial collaboration and coordination has been key to tackling this issue. This is equally true at a global, regional, national and local level

“The way COVID-19 rapidly spread all over the globe, it’s going to really create an appreciation of the whole approach of global health, which I think HIV can greatly benefit from. Someone in the US in Florida can appreciate that an infection in China and that would help in mobilising resources, including resources towards ending the AIDS epidemic by creating awareness around global health.” (Academia and research)

“The importance of coordinated action between the federal level and states and municipalities.” (PCB Member)

The exceptional nature of HIV has created exceptional collaboration

“I think in the HIV world, we've seen devastation and we've also seen success. It's one of the few areas where scientists don't fight with each other in a hurry. So it's a really big community. It's a community that doesn't differentiate, that's like a big extended family. And I think that's what sees us through, has kept us together and focused most of the time.” (Academia and research)

“AIDS has always been one of those catalytic issues that has managed somehow to bring together very diverse people from different ideologies to see a common goal - always been this sense of collective passion and drive and excitement to see that this is possible.” (Donor)

The places where the gains have been greatest have been when the issue has been tackled in a systemic manner

“Some countries who have better health systems, good funding, laws that don't criminalise sex workers etc., they are doing much better than the countries that are more conservative, have these laws, lack of funding.” (PLHIV network)

“What has contributed to advances in Brazil include a robust national AIDS programme, strong state and municipal programmes aligned with the national one, significant resources from the Brazilian government, the national health, significant changes in legislation to include diagnostics and treatment of all people, the mandatory licensing of medications leading to the reduction of prices, the criminalisation of discrimination of people with HIV or AIDS, and cross-sector dialogue, partnership and collaboration.” (PCB Member)

“This total football approach with adequate funding, which means the whole of government, all sectors you were able to work, all sectors, horizontally at national level – but also we were able to work very fast with the local levels, the sub national levels. And also the other sectors – not only the health sector. ... And I thought that was very, very important. ... we were also able to ... encourage the key affected populations to form their

organisations to give mutual support, but we from the government were also able to support them. And that is something new here, and I found this a very effective way of working, which actually we are doing now with the COVID epidemic as well.” (Individual expert)

Successful collaboration across sectors, especially the collaboration between governments and communities made a huge difference

“There are still between 100,000-150,000 people that need to be tested, most of which are part of the vulnerable populations. They lack access to everything and are discriminated against. We have made a lot of progress in reaching these populations by articulating with civil organisations that have access to and programmes with these populations.” (PCB Member)

“There has been a certain amount of progress in terms of promoting PrEP in the region. And this is mainly because of community based organisations, partnering with government and also with the help of UNAIDS, other partners and other UN goal sponsors.” (Civil society organisation)

... As well as collaboration between medical practitioners and communities

“I’m constantly amazed by my medical colleagues, who are unaccustomed to engaging with civil society.” (Academia and research)

“An example of one of our clinics in rural areas: doctors are elites in our countries. For a peasant woman who has never been to school, the doctor is a god. I tell my doctors that the patients are your bosses. Doctors greet patients by saying “Hello my boss”, which is strong in our language. In this way, we [the patients] are being healed before we even receive treatment. These are little things that have meaning and value and that help doctors do their jobs and care well for patients.” (PLHIV network)

This spirit and capacity for collaboration and global solidarity has waned over time

“In the early years it was very tough because no one wanted to talk about it and putting AIDS on the agenda was tough. If you worked on AIDS, you must be gay and you were very discriminated against by association.” (Individual expert)

“I think that the new generation, there are more people who are involved because it's a job. You know, they applied for a job, they had the profile, et cetera, but the old guys like me, I think we all have a personal history.” (Civil society organisation)

Multi-stakeholder collaboration has been piecemeal or ineffective

“So we spent years talking that the approach should be multidisciplinary, that you need to have a multi-stakeholder engagement, but at the end, our response was very vertical, very isolated. So to me, one of the challenges for the new strategies is to see how it combined with the agenda 2030.” (Civil society organisation)

“This kind of unified response is happening in a piecemeal way, depending on the country directors.” (Civil society organisation)

“If we were working more together, collaborating, and accompanying, we would eliminate AIDS. Infected people, the communities, the public sector, the scientists. Everyone working together.” (PLHIV network)

Challenges

People don't know how to collaborate effectively

“There's a funny thing that goes on in the multilateral world. Everyone talks a lot about cooperation but their own lenses are so tightly defined that their own space for manoeuvre and notion of cooperation is so small. Their notion of cooperation is getting someone else to do what I want them to, or helping me with my objectives.” (Donor)

“People have been saying for years that we need to all work together, but it doesn't happen because everybody is defending their own ground and area. It's very hard to bring people together across different lines of thoughts/responsibilities.” (Private sector)

“Organisational dynamics are another challenge. You often need coordination across ministries and across organisations. For example, to address prevention in adolescent girls and young women, you need coordination between the education ministry and the ministry of health. That creates challenges.” (Donor)

“We talk about integration but there are no real partnerships.” (Civil society organisation)

Strategic questions

What is the role of private sector in the HIV response?

The private sector is one actor that respondents had significant divergent views with regard to their place in the HIV response.

“Employers who are very close to their employees, on the ground, can be very effective. They're very present. That's one of the channels that we need to use.” (Private sector)

“Cipla and other generic companies driving down the cost of generics drugs significantly.” (Individual expert)

“COVID is happening during an era of radical privatisation and commercialisation and corporatisation of health care and we need to remind ourselves of how dangerous that was with HIV and how the public sector showed us the way.” (Donor)

“Because of the multi-dimensionality of the problem, there needs to be an entity that says this is how we stitch it together. And in this particular country, this is how it should work, and this is how you know if you're having success.” (Donor)

“Private sector can be involved in advocacy, workplace programmes, and innovation.” (Private sector)

“Since COVID there is a realisation of how important health is and maybe it's time to use this opportunity to understand how important health for the company is.” (Private sector)

“UNAIDS can also engage employee organisations, such as ILO. ILO created a document on AIDS 15 years ago. Since then there's not been an update. ILO should be active and should be brought in.” (Private sector)

“UNAIDS should look at partnering with the private sector in many areas, not just for funding. In the beginning it was more open, and more of a real partnership but the private sector lost interest in the beginning of the century so not only UNAIDS' fault.” (Private sector)

“Has UNAIDS really thought about better engaging the private sector in a way with the right governance frameworks around it, to avoid any perceived conflicts of interest?” (Private sector)

“My personal reflection is that the UNAIDS have not really taken advantage of, or worked strongly or closely enough with the private sector. I appreciate some countries have a level of perception around conflicts of interests, etc., but I think those can be managed and we have seen them managed elsewhere.” (Private sector)

How to strengthen collaboration between communities and the public sector?

“We need to improve the comprehension of the fact that we are complementary and that there are no rivalries. What the community does can have limits, and what the public sector does as well.” (PLHIV network)

“When we talk about community systems strengthening ... it is about the communities that are outside who will make your health system resilient and sustainable if we can play meaningful roles in them. So we need to invest in the communities, in those community-led responses that will reach out to those that don't trust their government services. And I think it is a way that we can really make a difference, is by ensuring that that is invested in.” (Key population, women or youth network)

“Most of the time when I look at the previous ways that it has been dealt with, they [UNAIDS] are mainly trying to tackle the civil societies but not the government. And then civil societies and NGOs are quarrelling with the government. So the UN agency must invite the governments, look into and make sure that the governments buy their ideas in the coming strategies.” (PCB Member)

6. The response must be granular and context specific

Overview

HIV manifests in different ways in different communities and contexts

“One of the challenging characteristics of HIV is that it is the same virus, but essentially a variety of different epidemics with different populations.” (Donor)

“Now we have a deeply differentiated pandemic that is centred in communities that are the most marginalised.” (Academia and research)

“What's really important to understand going into this is that people who use drugs are unique amongst key populations. In order to prevent HIV transmission, amongst people who use drugs, you need different commodities and different interventions.” (Civil society organisation)

“Although we're dealing with a pandemic, its distribution is not equal globally. And even within countries or regions, you have pockets of places, communities that are more impacted than others. And so you have to go into your highest priority and highest burden areas.” (Academia and research)

The strategy that is developed therefore needs to be granular and context specific. This means focusing on national, local and community contexts

“As long as we try and do the same thing for everybody, you're going to be where we are.” (Academia and research)

“I don't believe in the added value of even having a global strategy, because the difference between countries among countries, is so huge, so big difference in problems we face, huge difference in priorities we tackle.” (PCB Member)

“The strategy should be global, but it must also necessarily be made specific to each country and how the epidemic plays out there. We cannot have the same approaches even if the general goals are the same. We need regional cooperation then adapted to the country level.” (PCB Member)

“So a more granular approach is needed - it started being addressed in the current strategy - specific regions, the whole idea of fast track countries and cities, a more granular approach to key populations and that the interventions are fit for those key populations.” (Civil society organisation)

Challenges

There is a gap between rhetoric and reality

“We’re not yet built for creating a specific enough response, that’s tailored to populations and tailored to geography enough that we can actually reach those people that are not reached by generalised programmes. We give a lot of lip service to it, but we haven’t actually built the programmatic response that would achieve that.” (Academia and research)

The indicators and data available are insufficient

“We extrapolate from one or two studies and apply it everywhere, but what works is different in different places.” (Private sector)

“So something that concerns me more, the more I understand and am exposed to it, are countries with larger populations and presumptions about the epidemic that they had. So what do we do when the epidemic we thought you had in a country, is not the epidemic that you have? How do you shift the thinking, how do you shift the response and develop/redevelop that response, and how do you explain why we missed it... Did it change or do we miss it the whole time? And that concerns me.” (PCB member)

Strategic questions

How to ensure responses are based on granular, context-specific assessments?

“Don’t be global in your assessment. For example, don’t say ‘in Africa things are like that’, specify more, look at specific countries and even within the country, distinguish between the population. Look as granular as possible.” (Private Sector)

“Need to strategize more specifically, in a more granular manner based on the data that is coming, on the epidemiological situation, understanding the KP that are driving the epidemic. The underlying factors that hindering the achievement of targets.” (Civil society organisation)

“When you look at a country like Rwanda – you have had a civil war, the whole social infrastructure has been decimated, the economic infrastructure, yet in 20 years they have done remarkably. Why? There are still not a rich country... but they manage what they have very, very well. But it also goes to people’s attitudes. There is a sense of public service, a sense of commitment ... you go to lots of clinics in Rwanda and 90-90-90 is in practice. Then why is it that in Indonesia that things are so bad? That also has to be related to social attitudes to the human rights problems. And a weak health system as well, but a stronger health system than many other developing countries, but their HIV statistics are shocking, and again, not through a lack of financial resources. ... I think we need to dissect it on a country by country basis and then say ‘Well are there some commonalities or not?’ You

know we are pretty good at looking at universal goals and so on, but how to really translate how these factors impact us?” (Individual expert)

What are the difficult conversations that need to occur in relation developing a granular response?

“To stop the epidemic with adolescent girls and young women you need to be dealing with education, gender based violence, position of women in society, economic empowerment, etc. It’s therefore extremely challenging. You can’t just go and buy more and better drugs.” (Donor)

“I get very angry when people say, which they frequently do: ‘we know the answers, we must just implement’. We have no idea what the answers that are for adolescents the figures are getting worse as you’ll know, AIDS is the leading killer of adolescents in this region.” (PCB Member)

“I would argue that not all adolescent girls and young women are equally vulnerable to HIV, and that we need to actually have those conversations to get explicit. because it is not just adolescent girls and young women in key populations that are vulnerable, there are particular geographic locations where the vulnerability is huge as well. But we need to have those non-generalised conversations, and recognise where there are actually really explicit vulnerabilities to HIV – and other poor health outcomes, and gender based violence and all the things that come together to create vulnerability to HIV. But that is a very difficult conversation to have.” (Key population, women or youth network)

How does UNAIDS support this granular and localised approach?

UNAIDS has an important role to play at a country and local level

“At the national level, all parties are conflicted - having UNAIDS as an independent neutral and legitimate international voice is invaluable.” (PCB Member)

“Start decentralising more and provide on the ground assistance, rather than so many people at HQ. The programmatic assistance needed is on the ground and less so at regional offices or in Geneva.” (Academia and research)

“The key role that UNAIDS can play can be the role of trying to ensure that all of those elements required for prevention come together in specific country contexts. It can leverage its status as a UN Agency, relationships with different partners, to help bring things together.” (Donor)

“UNAIDS needs to use its leverage at country level to be much more powerful in advocating for governments to take responsibility for HIV/ AIDS and investing in the health of its population.” (PLHIV network)

“The most important thing is to have the presence of UNAIDS, not the co-sponsor, but the secretary itself at the country level, because with competing priorities at the country level it's difficult to make sure that the targets being set at countries are actually being achieved in terms of human resource that will actually facilitate UN country teams at the country level.” (Civil society organisation)

“UNAIDS could also explore further how to share knowledge and experience across different countries and experiences, testing, or supporting initiatives that test different strategies to reduce the number of infections and also to reduce the abandonment of treatment especially amongst vulnerable populations. It would be useful to share experiences between countries with similar populations sizes and characteristics such as poverty levels, immigrant populations, large numbers of homeless, and with similar epidemics.” (PCB member)

“Start decentralising more and provide on the ground assistance, rather than so many people at HQ. The programmatic assistance needed is on the ground and less so at regional offices or in Geneva. Then perhaps it can carve out certain areas so it doesn't duplicate what WHO is doing.” (Academia and research)

“Work really hard and focus on the 30-35 countries that account for 90% of infections. Keep a minimal presence elsewhere.” (Individual expert)

However, the strength and credibility of certain country offices is questioned

“It is struggling for visibility and it's not at the table anymore, domestically.” (Academia and research)

“In many respects, UNAIDS' reputation is grounded in its frontline country-level staffing. The extent to which it's effective in its affected populations is dependent on having very

HOPES AND EXPECTATIONS OF THE STRATEGY PROCESS

PERSPECTIVES ON THE CURRENT UNAIDS STRATEGY

AREAS OF ALIGNMENT

AREAS OF DIVERGENCE

A FEW CONCLUDING REFLECTIONS

good people in those roles. It wouldn't be controversial to say that there's a mixed history there in terms of people in those roles.” (Individual expert)

“If you have one person in the office responsible for partnerships, that's not enough.” (PLHIV network)

How to address the shift in mind-set required to move from a top-down to a bottom-up approach?

“It would require a mind-changing exercise - from working in top down approach to completely reversing the whole process to account for the data coming from the field - most important thing - joint continuous work and capacity building to change the style of work or regular work in countries. In many cases the political commitment at a national level is there, but it lacks some kind of systematic channelling in the hierarchy to the field level.” (Civil society organisation)

7. Mobilise exceptional political leadership

Overview

Visible support by influential people and political leaders has been significant in the HIV response

“In the early 1990s, our Princess sat at a luncheon table with HIV+ people at a time of very high stigma and this was televised all over the country. When the public see that high level leaders who they highly respect don’t discriminate, this impacts their behaviour too.” (PCB Member)

“I want to highlight one highly influential person. He was a musician... at the time when his career had peaked and when he was really truly a celebrity, he found out that he had HIV and took a very courageous step to come out and say, look, I have HIV... he actually came to my secondary school. When he came to the school, he looked quite unwell ... I remember recollecting to myself, ‘what a courageous thing to do when you’re really very unwell, you’re unsightly, probably scary to look at.’ And now 15 years later, looking back and seeing how a single individual, probably did a lot to create awareness and to try and dispel stigma associated with HIV.” (Academia and research)

“Look at the countries that have done best on HIV and AIDS on the continent. For example, Botswana, Rwanda, Namibia. One of the things they have in common is HIV and AIDS was a priority for the president and the cabinet and those governments. The minister of health knew every month at the cabinet meeting, the president was going to ask, where are we? Did we make progress? Did we achieve these targets?” (Civil society organisation)

“In the case of Uganda the leadership readily acknowledged from the word go, that we had a formidable problem in the country and drummed up support take measures, whether it was prevention or actually championing for treatment.” (Academia and research)

“Strong political leadership when around 2001 there was the first UN special session on HIV Aids convened by SG at the time - Kofi Annan who demonstrated leadership and got wealthy countries to commit 0.75% of their GDP towards fighting AIDS.” (Individual expert)

The opposite is also true

“Anywhere there is a lack of leadership or commitment or resources or technical focus when it comes to HIV, the void will be refilled by the virus.” (Civil society organisation)

“We could be certain that there was going to be a global pandemic and we could foresee what the challenges of that would be if it meant that being around other people was going to transmit it and globalised systems ... WHO absolutely predicted this, we all knew this, but we have a failure of governance and of leadership globally to take this on. And that’s scary. That’s a fundamental challenge I think.” (Multilateral/ Intergovernmental organisation)

*“One of the things we've learned very clearly in COVID is that ... the leadership of a few powerful States has the ability to either unwind or build the international community.”
(Academia and research)*

Strategic questions

The strategic questions in this section pertain specifically to leadership of UNAIDS – both as an entity and the leadership required of its executive director. These questions should be read in conjunction with the theme “Mobilise exceptional leadership.”

What leadership role does UNAIDS need to take?

“UNAIDS has the power to stimulate countries to do things in the right way. This is the successful story of UNAIDS.” (Civil society organisation)

“To keep donors happy and to keep a sense of momentum, you have to tuck away inconvenient truths.” (Individual expert)

“UNAIDS has an obligation to be bold and brave, because if you miss the chance to say what should be done, then it may not be said. If in doubt, be strong and brave.” (Individual expert)

“UNAIDS, and for that matter probably WHO as well, it is very important for these organisations to respect the country's sovereignty and to be neutral, because different countries have different sensitivity, political sensitivity, and therefore I think UNAIDS is still relevant, we have got to get technical expertise, there is a lot of technical expertise we still need, up country we need assistance from UNAIDS. But at the same time I think UNAIDS also has to play a neutral role, rather than putting pressure.” (PCB member)

“I hope that the UNAIDS have consultation with countries and UNAIDS also must have the ability to listen. Because they have many countries that are doing things and UNAIDS must not only dictate to those countries, they must have the ability to listen to what countries are doing to reach the target.” (PCB member)

“In the context of powerful and conservative governments and churches, UNAIDS has some influence, but not a lot. Any agency of the UN is in a tough role ... where you can't speak directly about the government. So UNAIDS tends to tread the middle ground, which makes you look as if you're part of the problem.” (Civil society organisation)

“I do think it is time for us not to be risk averse, but instead we have to increase our risk appetite and lead – be ambitious and lead.” (PLHIV network)

“We need a bolder, more radical statement that we know is not going to come from states, is not going to come from UNAIDS, because those are diplomatic bodies, they have to say diplomatic things.” (Civil society organisation)

“I think we have to find a balance between a diplomatic phrasing, so the fact that ‘regardless of legal status’ was the trigger for everybody, I think I would be quite happy to not use that sort of language. But I don’t think we can miss out ‘key populations’ or ‘criminalisation’ or ‘human rights’ and the role that human rights and defending human rights has in ensuring success in HIV. So I think there is a very difficult path to walk along not watering it down, which UNAIDS has so often done in the past.” (Key population, women or youth network)

“We’re always saying: ‘be guided by science’, yet, we can’t be brave enough to mention harm reduction for fear of upsetting the US. Then it becomes really difficult to address laws and discrimination, especially on more complex issues.” (Key population, women or youth network)

“There’s unfinished business in terms of changing the nature of power, such as treating public health as a public good. We keep skirting around the big questions.” (Civil society organisation)

“I’m not assuming that the UN can change the systemic issues. But it can be unequivocal about the challenges facing people. It must articulate an understanding that the epidemic is as a result of systemic problems.” (Civil society organisation)

“UNAIDS representatives at country level should no longer be diplomats. If we’re going to address the stigma and discrimination, we have to be bold. We have to identify where those weaknesses, challenges and those gaps are and be able to say to countries in a very bold way, these are the specific things that you need to do a country level, to be able to fully address the issue of stigma and discrimination.” (Key population, women or youth network)

What kind of leadership is needed from the UNAIDS executive director?

“It matters that the executive director of UNAIDS is appointed by the SG and is accountable to the co-sponsors, as well as accountable to the PCB. Because that means that there’s no recall mechanism for the head of UNAIDS... That level of bureaucratic insulation can be dangerous at times ... but it’s also insulation. It lets them say things that other agencies can’t say, gives them some flexibility and some responsiveness... And so part of what the strategy can and should do is to say, given that UNAIDS has this foothold in the United Nations, and therefore has all of the power that comes from that, the legitimacy that comes from that, access to governments, all of those things, but also has this insulation, what can it leverage in that? How is it being smart about the space that it inhabits?” (Academia and research)

“We hope that the energy of people like Winnie will build more courage, because we felt it becoming more conservative in its language.” (Civil society organisation)

“From what I’ve seen of Winnie, she seems to be strong and brave. That is needed. I sat with her on the high level panel on access to essential medicines. Winnie and one or two

others dissented. I told her later that I should have agreed with her dissent ... I thought it wouldn't get through Wall Street and I was too cautious.” (Individual expert)

“Leadership of UNAIDS is critically important and a source of some uncertainty right now. Up to now, I have not heard any clear message from this new Executive Director about policy. That makes many people working on HIV/ AIDS unclear about the policy from the central level, about how should the country move forward. My wish is to hear more.” (Civil society organisation)

“The change in leadership with Winnie I think is great. And it's totally exciting to have her at the helm. ... there were concerns...questions about if she would be vocal around sex workers... concern about whether Winnie would willing to take on and be the champion on issues for people and women who use drugs.” (Key population, women or youth network)

“The role of the ED is very important in convincing countries to do the right thing at the right time. A previous Executive Director came to Thailand to speak to the Prime Minister and the Minister of Health. That helps things move faster. Policy advocacy like this is very important.” (Civil society organisation)

“Winnie needs to find her voice and align that to other voices in terms of leaders that can be heard.” (Individual expert)

“There is nothing like success to breed success. So worry less about a public persona profile which typically the ED's have had but to keep quiet, to take maybe not a back seat, be less visible but quietly get on with the job.” (Academia and research)

“It's about an externally facing collaborative style of leadership that has not always existed within UNAIDS.” (Academia and research)

“As important as the current leadership is, it is disconnected from the power-base that has driven and sustained the organisation so far. Those organisations have dissipated and gone back to the shadows. There needs to be a bigger drive to bring some of the key thinkers back. Otherwise the leadership is isolated and bereft of strategic ideas.” (Academia and research)

8. The AIDS response needs to be properly financed

Overview

When the global community significantly invested in HIV, the scale, speed and focus of the response saved lives

“The world invested a lot in HIV, and that is why there were so many results.” (PLHIV network)

“The game changer there was 2003, the creation of the global fund to fight AIDS, TB and malaria and PEPFAR. There was a multilateral and bilateral and an unprecedented attempt to make any viral therapy treatment for an infectious disease universally available. It required billions a year and, and that money was made available.” (Academia and research)

The AIDS response has to be backed by funding

“You can have a perfect strategy and a perfect structure, people with perfect competencies sitting within that structure. But if you don't have funding then you're stuck.” (Donor)

“Generally, any strategy can look good on paper. It doesn't mean anything on its own. The question is: Is it backed up by a serious budget? That's where the credibility of a strategy really lies.” (Civil society organisation)

“I doubt that the new strategy is going to say anything very different about structural barriers and zero discrimination. But the real issue is that we're not investing nearly enough. It's getting the money lined up behind the strategy.” (Civil society organisation)

Challenges

The global AIDS funding architecture is a challenge

“There is a global financial architecture that really makes it hard for countries to respond to HIV.” (Academia and research)

“Global financing, health financing architecture is one of the problems that we have right now and also one of the problems or one of the challenges or obstacles that will stop us from moving from these silos into a more integrated approach towards health.” (PLHIV network)

“Global financing is predicated on domestic financing for upper and middle income countries - need to be spending more on their budgets on HIV.” (Donor)

“The Global Fund for instance decided to cut the middle income countries from their portfolio, just because they are middle income countries! Without looking at the pockets of

problems within those countries ... in my region for instance, Latin America, it is a region that is completely forgotten in these strategies and funding allocation etc., because we have 90% of the governments here paying for the treatment, but they are not doing prevention! And even if paying for the treatment, people are not looking to the micro lens, and not seeing the inequalities! So trans gender people, key populations, women and violence, etc., etc. – everybody is just left behind! So it will be interesting that definitions in the future could be more based on the country's realities, not in the countries' macro economic data or not a general area as treatment.” (Civil society organisation)

“Middle income countries– I think that they are discriminated right now when it comes to the price for medicines. So they have somehow are abandoned to their success: ‘okay, you are rich, you can pay.” (PCB Member)

“Public health has 6% of the budget... And within this money, you have to have a choice. And when you look at the mortality rate from HIV, it's not about first five or six positions. And it means that the priority is not for this article in the budget.” (PCB Member)

“You will never achieve a hundred percent of national financing because of the marginalisation of this problem in our societies.” (PCB Member)

“For some countries, PEPFAR and Global Fund represent 60, 70% of the response, and when it comes to treatment specifically, maybe even 90%. So if that funding is not there, that's a serious constraint.” (Individual expert)

The funding landscape for the HIV response is shrinking, not least because of COVID

“And so there's a jockeying for funding writ large, and that's making it very hard right now to figure out how to get enough money.” (Academia and research)

“The United Kingdom GDP shrunk by 20% in the last four weeks. I think people have no sense of the crash that's coming economically. Over a hundred million people are probably going to go back into poverty ... It's going to mean deprivation, more exploitation child, labour, education, more sex work.” (PCB Member)

“We have a very big risk under COVID. We are a middle-income country and we risk losing financing ... It was planned to gradually transfer from Global Fund to the public budget. But right now, that doesn't look realistic.” (PCB Member)

“One of the biggest uncertainties is the funding of the global response, because COVID has a stranglehold on the economies of countries that are at the epicentre of the AIDS epidemic.” (Civil society organisation)

“The economies of countries that have anchored the funding of the global response are also facing more uncertainty, for example, the US through PEPFAR. If the US can't continue to make that contribution, other countries will wake up finding themselves unable to sustain the big treatment programmes they're running. The question of funding is a big one, for the whole multi-lateral system to contend with.” (Civil society organisation)

“Less multilateralism means less money for development... You have to tackle your own problems. That means you have less money to share with others, less money for international assistance means that we will have more failed states ... in lots of specific issues like responding to the HIV AIDS epidemic. Because we know that lots of countries depending totally to the international assistance.” (PCB Member)

“I think COVID is a concern because even pots of funding that were for drug policy or harm reduction or HIV, are being diverted.” (Key population, women or youth network)

HIV in a world of competing interests and priorities

“Long-term foundations that have been very reliable on funding more innovative initiatives are moving on to other priorities.” (Civil society organisation)

“We have targeted Fast Track 90-90-90, and then 95-95-95 by the year of 2030. I know these targets are aspirational, however we must be careful with the limited resources. To do coverage from zero to 80%, the higher the coverage you go, the more difficulties you hit. This is the diminishing return. And now we are facing the diminishing return. So to reach the last mile ... we must put them as the first mile and invest most of our resources to tackle them head on... So we must prioritise these groups and put maybe 60, 70 or 80% of our resources and action onto these groups!” (PCB Member)

“Maybe we will have to accept in a begrudging way, that 90% is okay... Just because of its place in the world, because I think that last 10% for all of those diagnosed, those who know their status, of those who are on treatment or virally suppressed, it is going to be incredibly difficult; and it is not going to be incredibly difficult because we can't do it, or we don't want to do it, but just because the very ingredient that we count on to make all of that happen, which is political commitment, which is constant funding, which is all of those things – those variables are changing in front of our eyes.” (Professional society/ association)

“The last 10% is less reachable. So first of all I would think about the cost effectiveness considerations, because the normal things that you would expect to be less costly, they become more costly when you are reaching those last 10% - and this is something to keep in mind and to understand and take as a reality.” (Civil society organisation)

Strategic questions

How to strengthen the global HIV response in the context of shrinking global financial resources and the long-term economic impacts of COVID?

“We make the strategies, and then go to countries and ask for the resources. It is important to look from the start, at how to resource the implementation of the strategy, to ensure that we have the capacity to actively implement the strategy.” (PCB Member)

“In a world with a deep economic crisis how to ensure that health attention, support and treatment is provided to all those in need?” (UN Agency)

“So you get a double blow, reduced global funding for HIV, reduced domestic funding for HIV. So UNAIDS needs to work with others to craft a new way or funding, an additional way of funding, HIV responses.” (Individual expert)

“PEPFAR wasn't created with commentary, ‘we'll be funding at this level for the rest of time’. What happens and what are reasonable projections about levels of funding, not just from PEPFAR, but from other sources?” (Civil society organisation)

“How do we ensure continuity of funding, particularly ensuring that national government fit HIV into core health budgets and supply chains. There is currently an over-reliance on the US for funding. How will this change?” (PCB Member)

And so that's a critical piece of figuring out how we look at debt, how we look at intellectual property, how we look at a variety of things that are structured into the world economy that make it very hard, they're huge barriers to overcome to then effectively respond to HIV.” (Academia and research)

“I have fear that there will be lack of funding – that is my biggest fear – and therefore we have to continue in Europe, in the Western world, in the more developed countries; that solidarity is so important, and that we cannot afford to cut development budgets, and we have to fight for more development budgets.” (Multilateral/ Intergovernmental organisation)

“I think one of the things that the UN system really needs to continue to work on, is the need for a public/ private sector partnership when it comes to HIV programming. We know that there is still a lot of money within the private sector, we know that the private sector have huge advantage in terms of efficiency and as well as accountability.” (PCB member)

“I think UNAIDS alongside other UN agencies is going to need to play quite a strong role as we come out, or hopefully when we come out of the current pandemic. You know that is obviously increasing national debt for many countries and what are the implications of that, and is there a way through the UN system that of course UNAIDS can be part of, that can help with different proposals around innovative financing or smart investments? (Private sector)

How to counter the politics of funding?

“Stop making funding decisions made on political considerations.” (Civil society organisation)

“Traditionally we are built on a neo-liberal foundation where the global north are donors and the global south are implementers, and therefore the governance of global health is actually being held by the global north because they have the power, and money is unregulated power, right? ... we need to rebalance geopolitical power within the global health governance.” (PLHIV network)

“The biggest example is the US. Super, super, super rich country, where the black people are dying from HIV and UNAIDS has done nothing about that. And why? You cannot do

anything at country level with black people, just because that country is the country that is paying for PEPFAR, and it's the biggest donor in the world. What about the population? That's why I'm saying to you I think this new design should really take a look on populations and not only on the frontiers [national borders].” (Civil society organisation)

How much should the strategy align with COVID?

“How will COVID impact the replenishment for the Global Fund, the continuation from Member States to UN agencies given the economic downturn in all countries?” (Key population, women or youth network)

“If you look at institutions concerned with HIV - when I look to 2022 at the Global Fund's next replenishment - the biggest issue on the world stage, in any scenario, will be COVID. If we're not talking about COVID at all during the next replenishment, it will be very hard to raise money.” (Donor)

“There are lots of resources that are needed to control the COVID-19 pandemic. And therefore there are going to be hard choices and decisions that have to be made including prioritisation and therefore we need to think very fast. We need to move very fast, make sure that the two epidemics are not competing... resources are going to be fewer, there's going to be competition for the same resources and therefore we need to see how do we make sure that we are not leaving one epidemic behind at the expense of the other.” (PLHIV network)

How to rethink who gets funding especially as it relates to middle income countries?

“Support the countries that are falling behind particularly those in Central and Latin America that are no longer priorities for international financing and that don't have strong domestic programmes or financing... We won't be able to eliminate AIDS if there are countries that aren't able to treat their populations due to cost.” (PCB Member)

“I think that there is time for Global Fund to become more flexible, more flexible in terms of taking into account the specific needs and especially of middle income countries. ... It's time to rethink the global fund strategy, especially towards, for example, this region, Eastern Europe and central Asia.” (PCB Member)

“Stop using World Bank economic classifications to lead decisions on which countries are eligible for funding. This is going to do damage to sustainability. Countries like Botswana and Namibia were upper middle income countries but probably won't be post-COVID. Resources need to flow where the need is greatest, which could include countries that are relatively wealthy but where there is no government support. This is not only about how we create sustainability mechanisms for civil society, but how we push a much bigger agenda around how HIV is addressed according to the need of communities rather than the economic classification of that country.” (Civil society organisation)

“Definitions in the future could be based on the country's realities, not on the country's macroeconomic data.” (Civil society organisation)

How to make a compelling investment case? And what to prioritise?

“We have to make a better investment case and a compelling investment case... we’ve got to be more circumspect about 1, how do we make this an inspiring investment? But at the same time, we be realistic about what it is that we can achieve and do that.” (Academia and research)

“The donors may shift their minds and see that HIV/AIDS is not the priority. This might be problematic, so we need more analysis to prove that it’s still relevant. We need more modelling and analysis that says we really need to not take our foot off of the gas.” (Civil society organisation)

How to ensure transparency regarding where money is being spent?

“When there was a lot of money around, we didn’t analyse very carefully what we were investing in. As a result some things that have not had the greatest impact have continued. I think we need a much sharper focus on looking at what works, what has greatest impact and really focus resources on some things. It might mean giving up some things. We need to understand, at an every day level, what brings the greatest impact, what is the most efficient use of the resources that we have. Not necessarily bring them to scale, but to focus on those and disregard other things.” (Individual expert)

“The development of the Global Fund provided two very important things. First, the system, which makes the HIV budget transparent. All global fund grants were available for anybody, through their website and then through reading the proposals countries sent through participation in CCM.” (Key population, women or youth network)

“I have done an analysis of how much money has been actually invested in the AIDS response through them over the past 25 years. It is an obscene amount of money, and they need to be able to delineate what they have actually achieved with that. I am not saying they haven’t achieved anything but they need to put the achievement up front in order to convince people that they are worthy of support going forward.” (Academia and research)

Areas of divergence

This section highlights three themes around which there is significant divergence of opinion from respondents, namely “Vision, goals and targets”, “The focus of the next strategy”, and “Is UNAIDS fit for purpose?”

1. Vision, Goals and targets

Overview

Divergence of perspectives on the usefulness of the goals, visions and targets

Those that feel they have been useful:

“That UNAIDS continues to enable the world to speak one language, have the same targets and work towards eliminating AIDS as a health threat by 2030.” (PCB Member)

“So I think right from the beginning everyone realised that these goals are very aspirational. And probably UNAIDS, rightly or wrongly, was ridiculed for it. But on the one hand it is extremely important to have these goals. If you look back the 3 x 5 WHO goals those years ago, that too was thought to be too aspirational but in the end, maybe had not met the time line but it certainly provided the catalyst for change.” (Academia and research)

Those that feel they have done harm

“Communication did a lot of harm in the last years at the UN with a series of slogans that meant nothing ... but I also understand that these goals at the UN, must continue to be ambitious because otherwise people do not put enough energy at least to arrive to 25% of the entire goal.” (Civil society organisation)

“Stop using “getting to zero” and “leave no-one behind” statements. I think they trip off the tongue so lightly, but they become meaningless.” (Individual expert)

“In the current strategy, there's a lot of talk around, ‘leave no one behind’, but in fact, we have left the key groups out and that's who's been left behind that.” (Academia and research)

“I think that communications and PR has become almost the number one game in the UN and in development, whereby it's all sort of messages for public consumption. It's all about showing that we've got results.” (Multilateral/ Intergovernmental organisation)

“And because we had also a lot of key messages going out with we are success movement. We are success... It is impressive to see how members states and other people who were not working in our field felt that it was more or less something in control... it's awful to see how people just forgot about HIV. It's awful. Just horrible.” (Civil society organisation)

“Previous strategies have contributed to the perception that AIDS is over.” (Individual expert)

Divergence of perspectives on how realistic the goals, visions and targets have been

Those that feel they were realistic at the time

“Around 2015, 2016, which is when the current strategy was developed, was a very exciting time in our response to the epidemic. So we'd seen how treatment access, for example, and the change in AIDS from one that was inevitably fatal to one that's chronic and manageable gave hope to a lot of people. At that point, we'd already lost something like 35 million people to AIDS. And suddenly we had these life saving drugs, at same time we've saw the impact of ARVS in reducing mother to child transmission, and in terms of use in uninfected people, in other words, PrEP to prevent it. And we also had medical male circumcision. So what we saw was a conflation of knowledge that gave incredible optimism. And I don't think it's unrealistic optimism for those 2030 targets being set.” (Academia and research)

“In the last 5 years, we've achieved good results. Not yet at the 90-90-90 target, but progress is happening and their support should continue.” (PCB Member)

Those that feel they are unrealistic, especially with new threats such as COVID-19.

“Eliminate aids infection, is for the birds. Nonsense! I don't see that happening ten years from now. Even discrimination, zero discrimination, I don't think it is possible! Maybe AIDS-related death – yes, we can achieve that, maybe – but the two others, I don't think so.” (Individual expert)

“Without COVID, my level of optimism for achieving the SDGs with relation to HIV was reasonable. But COVID has put a major spanner in the works.” (Academia and research)

Challenges

Lack of accurate, credible data

“With the government in this case of Venezuela, the main areas of intervention have been data because there is a huge problem.” (UN Agency)

“No one country has well grounded data on the number of key populations, how many people belong to these populations. For instance for the Russian Federation two years ago a report was issued... which says less than 0.02% of Russian population belong to MSM. It means that there may be, I don't know, couple hundreds of MSM for the entire country. – which is not right and in only Muscovy you can find tens of thousands of MSM. Only in one city.” (Key population, women or youth network)

“The data issue is inherently complex as well when you are talking about a population that is highly criminalised; data has to be collected in a really sensitive manner to protect

people’s privacy and their ability to participate, and it makes it a really high stakes process and to get sufficient data.” (Civil society organisation)

The way in which some targets are further elaborated mean that some groups and regions are being left behind

“I requested the Global Fund to offer a grant for displaced people but we don’t have survey data to analyse the HIV risk among these people and we couldn’t show their HIV prevalence and we couldn’t raise the funding for them –because it fell outside of the three key population groups. We need to reach them too. We couldn’t argue with the donor yet.” (National coordination mechanism)

“West and central Africa is still being left behind because in the planning of the targets; it was predicted that West and Central Africa is a region out of focus.” (PLHIV network)

“With the last strategy we were told that there wouldn’t be the component of sex workers in Ecuador. I asked - why was this component cut? I was finally told the prevalence in your population has decreased. The statistics show that it is much lower. But we know that there is underreporting. And the population of sex workers is growing. Leaving us out of the support puts us at risk.” (Key population, women or youth network)

There are numerous targets and priority areas that have no indicators to measure progress. This includes indicators for stigma and discrimination, community participation, political commitment and criminalisation.

“We’ve had some challenges there with the measurement and as a country, trying to determine who and how stigma should be measured and who should measure it ... So I can’t even give a current status report on stigma and discrimination.” (National coordination mechanism)

“We have a target of at least 30% of services delivered by the communities themselves. Until now, we don’t even have a way of measuring this. This target started in 2016 but if you can’t measure, you cannot change. We have a taskforce to work on this, but they’re taking so much time.” (PCB Member)

“What matters most is political good will. It’s not tangible and you can’t see results, there are no M&E indicators, it is dismissed easily.” (National coordination mechanism)

The current targets are insufficient

“What I’m learning from 90-90-90, it has helped push down AIDS mortality and AIDS related morbidities.” (National coordination mechanism)

“90-90-90: In itself it’s inadequate to get to anywhere close to the targets we need to for getting to a trajectory of the 2030 goals.” (Academia and research)

The way targets are met sometimes cause harm to the recipients

“For example, when you talk about the 90-90-90 and reaching that goal and therefore ending the epidemic by 2030, what we experienced is that the implementers are not caring

much more about the rights of people including the key populations... They don't care how they get people to be tested. How they get started on treatment and how their viral load gets suppressed. They only care about the numbers, but in the process, you're hurting people.” (PLHIV network)

“If you want to get to everybody to know their status, when we know that there are groups ... who are in an environment that is making them illegal as human beings... then that means that you're making those people even more vulnerable.” (PLHIV network)

Strategic questions

Do we have a common understanding of the language we are using when it come to goals, visions and targets?

“It has to be agreed to... the whole UN family, including the funding, like the World Bank and the regional banks etc, have to agree that ‘yes, this is our aim for 2030’ – and not some people say this and some people say this. Let’s have one agreed to formulation of what it is we mean by ‘end of AIDS 2030’” (Individual expert)

“‘Ending AIDS’ is only half the statements because it's actually ending AIDS as a public health threat, which means something very different from ending AIDS. ... I think this is fundamentally one of the challenges that we have in terms of progress is we these catchy phrases and it sticks and it sticks incorrectly... The first thing we need to understand is are we on the same page on what goal we're trying to achieve?” (Academia and research)

What should the goals, visions and targets for the next strategy be?

“Fear is that UNAIDS comes up with another ambitious target when we are far from close to reaching the target they put in their last strategy.” (Key population, women or youth network)

“In the last 10 years there were very strong targets set by the UNAIDS Joint Programme, in their strategies for people who use drugs and for harm reduction, which is brilliant. But what we are seeing is that they are not being met. ... That target was not only not met, HIV infections among people can inject drugs are on rise globally. And then nothing happened. There was no conversation about why this target was not met. What are the key gaps? How can we address them? What can we do better next time?” (Civil society organisation)

“We must have a real reflection on these objectives which are set for 2030 and with the new threats approaching. It seems that we will need to review this global strategy [the 2030 agenda].” (PCB Member)

“Continue setting ambitious targets like 90-90-90 or increasing them to 95-95-95.” (PCB Member)

“Why not do 90-90-90-90? We did 3/90, so why not 4? To consider the issue of AIDS-related mortality. If we do 4/90 and add the question of AIDS-related mortality, it will be a wake up call and people will see the progression.” (PLHIV network)

“I’m interested in targets, not only for the aggregate population, but it targets for subpopulations as well to ensure that those are not lost and that we put more pressure on countries to obtain accurate data on what is going on in those populations.” (Civil society organisation)

“UNAIDS will need to ... push for a new set of messaging around prevention. It may require some rethinking of our targets, our indicators around prevention our modalities of how we do prevention.” (Key population, women or youth network)

“My fear is that there will not be sufficient safeguards for civil society participation, especially ... making sure the community led targets and indicators will be coming to the strategy.” (Civil society organisation)

“I think whenever we’ve asked about putting more spotlight or attention on target setting or collecting information on criminalisation and social enablers, we’ll get the answer: we just don’t know how to model it. So it’s always something that’s put in the too-hard basket.” (Key population, women or youth network)

“The UNAIDS monitoring and reporting frameworks is very much both for UNAIDS programme and for the AIDS strategy. The real focus is around the big outcome, impact targets you know, like three zeroes, like 90-90-90, and such – and this is definitely the right way to go. But at the same time I believe there are needed some tangible targets that will be linked to those bigger level outcomes, but that would be more clear for people, more clear as to what interventions lie behind them, what should be done. (Civil society organisation)

“I’ve had conversations with people at UNAIDS about neglected populations. The response is: the information isn’t good, so we can’t really do anything.” (Individual expert)

How to ensure the targets are meaningful and appropriate for communities?

“I remember saying to someone I am not willing to say your slogans, these are for people in HIV for the jobs not for us living with HIV. There is still too much sexual violence, coercion, paedophilia even if they call it child marriages.” (Key population, women or youth network)

“I’ve invited people living with the disease into my PCB team. I asked each of them, do you know what 90-90-90 means? They didn’t know. Only one knew. You have a target approved at UN level but very few people feel that they own it, feel that they have to make it happen.” (PCB Member)

“Exploring community based community led interventions and community based and community led targets.” (Civil society organisation)

“Instead, consulting with communities and coming with goals and not appealing but meaningless slogans. The goals must have a deep meaning for people and call them to action.” (Key population, women or youth network)

“Humanisation of what the targets mean - the targets are people.” (Professional society/ association)

“These goals are good, but they need to be followed by clear guidance, clear monitoring to make sure that the outcomes and not hurting people... make sure that even when we have targets and goals, to make sure that they are being implemented in a way that respects people's human rights, that considers the different situations that groups and communities are facing, and that at the end of the day, we all benefit together.” (PLHIV network)

How to ensure that the data being used in decision-making and measurement is reliable, up to date and accurate?

“UNAIDS is producing very accurate data.” (PLHIV network)

“I am a big fan of their data group - they are awesome, really enabled better understanding based on programme results instead of surveys.” (PCB Member)

“The data helps us to understand where we are. When we go to the website, we get an idea of how the fight is going around the world.” (PLHIV network)

“The meta-analysis and reporting published by UNAIDS, showing progress in different countries, really helps us with advocacy for NGOs.” (PCB Member)

“I just quickly looked at UNAIDS data for example from 2019 and the first country was Kenya, and I looked at it is over 80% of people who inject drugs and UNAIDS is reporting that they have safe injecting practices. But we know this is not true; we know that this does not reflect reality at all.” (Civil society organisation)

“With UNAIDS we are seeing some data on criminalisation and the number of countries that criminalising use of drugs and I think it is something like 68% or something, so anyway sometimes there is real lack of transparency or explanation about how they arrive at some of this data. And we go to the meetings and we bring it up but it is never really explained. So it is kind of like ‘well how are we going to get anywhere if we are using the wrong data and obviously the data response, everybody looks to UNAIDS to collect the data.’ (Key population, women or youth network)

“UNAIDS have shown us how wrong modelling can be in the past. Modelling can guide us but should not taken as a bible, it should inform us - but we need concrete action, which are based on evidence.” (Key population, women or youth network)

“I think that everyone relies on UNAIDS for data. It is recognised as the data that should be used. It's therefore incumbent on UNAIDS for the data to be latest, most accurate, most focused. I think that strategic information and data is one area that UNAIDS really needs to focus on.” (Individual expert)

“I think UNAIDS plays a very critical role because UNAIDS establishes the targets and the trajectories for the world, but also for different countries.” (Academia and research)

How to ensure accountability and impact?

“The crisis we’re facing in HIV is the political commitment. We’re in a situation where governments say the right things and don’t do the right things and are not held accountable.” (Civil society organisation)

“Many African countries have committed to the Abuja Declaration, but how many are actually financing 50% of their health budgets? That’s what UNAIDS should be addressing.” (PLHIV network)

“The most important thing is to have the presence of UNAIDS not the co-sponsor, but the secretariat itself at the country level, because with competing priorities at the country level it’s difficult to make sure that the targets being set at countries are actually being achieved ... It’s really important to have a UNAIDS person in there, and it has to be a dedicated person ... especially at the time when HIV is not becoming a priority anymore, it’s very important.” (Civil society organisation)

“Almost every five years, we sign these political declarations, but there is nothing that actually holds governments accountable to ensuring that those commitments are met.” (Key population, women or youth network)

“We need to have a very clear mechanism to hold people accountable. The periodic evaluation should be critical. We need to evaluate if the intervention resulted in anything? Did it add anything? Change the lives of people? What are the results? See the impact short-, medium- and long term. People need to see the results.” (Civil society organisation)

“I think they need to take more of a political leadership role, rather than just being a bit more of a convener rather than a leader. And I think taking and driving accountability within UN members is really a role that they are in a unique position to be able to play, and I think it is probably needed more now than ever, in the COVID environment that we are in.” (Private sector)

What should the communications strategy be?

“This new strategy needs to have a strong section on communication.” (Civil society organisation)

“How do we celebrate the accomplishments but at the same time also communicate to the world that there’s much work that needs to be done? I think that’s a very tough balancing act.” (Academia and research)

“So the complacency I think is a very worrying piece and that needs to be tackled. So we have to almost remind everybody that we still have nearly a million gets taking place every year. We still have some 20 million people to be initiated on treatment. And we still have to

prevent nearly one and a half million infections, which translates to about four for the half thousand infections a day.” (Academia and research)

“I know that at the World Economic Forum, Winnie was in two sessions. One was a re-launching a business coalition on AIDS to bring business together. In another session it was bashing business. That approach of having very different messages is not going to work well. You need to make choices because you undermine either positions by doing the opposite of what you’re saying, and you need to have a very consistent discourse.” (Individual expert)

“We can't promise you something and then continue to fail to deliver on it and then blame the complexities of the world. We need to instead be honest about the fact that: ‘you can't do this without us. This isn't about us delivering things for you. It's about you delivering things where we're helping guide you, we're helping convene you to do that, we're helping to hold everybody's hand and bring it all together to provide this space for this. But it's your responsibility.’ And that is everybody from the government of Rwanda to the government of the US.” (Multilateral/ Intergovernmental organisation)

“It is important that the framing is similar to the last one, that it is sloganized to a degree. It's important to find a way of packaging that it is easy to understand but has real goals that can be seen. That was the really good thing about the current strategy. We shouldn't lose that. We have to end up with some very key targets that are ambitious and achievable. There's no point in setting targets that could never be achieved.” (Individual expert)

“The speed of the response, particularly risk communication - has been amazing, and the despite misinformation and fake news there is something to be learnt from the speed and coordination of response from government and media. Having people stay home and shift behaviour is not easy, yet that has been possible in relatively short period of time.” (PCB member)

2. How broad or narrow should the next strategy be?

Overview

There has always been the understanding that HIV/AIDS cannot be addressed in a siloed way but needs an integrated, systemic and collaborative response. The SDGs themselves are built around this idea of intersectionality and the previous strategies have been developed on this premise. This strategic orientation has further been highlighted in this synthesis (for example references to the need for a dual biomedical and human rights response, addressing structural drivers and inequality and collaboration and partnerships).

However, there are a diversity of views about how that has played out in reality and what this means for the next strategy.

“Health doesn't exist in a vacuum. The global HIV response really brought that to the fore, but it's kind of died down and become institutionalised and become too just focused on biomedical interventions and thinking that those are going to be the answers.” (Key population, women or youth network)

“UNAIDS have existed for 20 years as a single disease organisation and have not been able to adapt very well to the more integrated primary care environment. Only disease specific lobbying - I think there are questions about what their role is 20 years later, now that we are way past the emergency response.” (PCB Member)

“HIV has been accused of being the movement that created those siloes! I don't think so! Because that is not how the community works. ... The siloes come when the community organisations apply for funding, that is where the siloes come. So it is not about communities creating these siloes, it is actually the people who have been screaming you know ‘working beyond siloes’ are the ones that actually created those siloes – which is the donors.” (PLHIV network)

“Can UNAIDS, under its new ED and new strategy, successfully integrate the AIDS response into other health, or will they defend it as a silos?” (PCB member)

“There have been a lot of efforts to bring AIDS out of isolation and put it into a more one health context, a universe of access to health. Here UNAIDS has always been at the forefront and it should continue on this path.” (Multilateral/ Intergovernmental organisation)

In addition, in the context of competing challenges and priorities, including COVID-19, shrinking global and national funds, the changing political landscape, and the peculiarities of HIV, there are divergent opinions about what the focus of the next strategy should be.

Strategic questions

How does the AIDS community continue to hold space for HIV while also contributing to the global health response?

“How much does the AIDS community pivot and figure out how to simultaneously hold space for HIV and control the narrative around HIV to ensure that it does not fall off the agenda while also figuring out how to make the case that investments in HIV can also be investments in the global health security agenda that's out there.” (Academia and research)

“The key here is how can UNAIDS make itself relevant across all SDGs, but at the same time, keeping the focus and not losing the priority that AIDS is still a pandemic.” (Civil society organisation)

“If we start talking about everything, we will end up with nothing to be honest, and that is what is worrying about the conversation on UHC [Universal Health Care], ... because you talk on things that are so broad, and nothing will come out of it.” (PLHIV network)

“There is a donor fatigue obviously happening on HIV, and one of the way out that ... is around integration into broader health conversations ... but we cannot create a dichotomy out of this, it is not single disease strategy versus integrated health systems, it is not like that; we have to invest on both.” (PLHIV network)

What should be the focus of the next strategy?

There seem to be three broad responses to this question. The responses are not necessarily mutually exclusive, rather about where different respondents think the emphasis should lie, and some rationale for their stated emphasis.

1. The strategy has to focus on HIV in the broader health and development context because...

... It needs to anchor itself within the SDGs

“I think that the strategy will be successful if it is built in dialogue with the agenda 2030 and not like I'm this part of health. No, I'm this part of development. Health is a very strong part of development.” (Civil society organisation)

“This upcoming strategy is very important considering that restructuring the strategy towards 2030, the issue that the COVID-19 pandemic presented in front of us is a very big one in terms of finding that balance all across the SDGs.” (Civil society organisation)

“We need to think in the era of the SDGs, which is much broader than a single disease. Comes back to the questions of efficiency. You can't deal with this in a single disease way. You will need a more comprehensive approach. Where more narrow interventions, on a single disease, is creating more susceptible. So we need to programme into wider developmental strategies.” (PCB member)

“There are lots of people in global health are taking the SDG goals very seriously. And when they look at the science and they look at the economics, the health economics in their minds, they are clear that the world cannot afford a disease specific agency or Joint Programme. I think COVID may exacerbate that. I think that in people's minds, you can't afford 1520 programmes for specific conditions. So you have to wrap it up into integration.” (PCB member)

... The age of AIDS exceptionalism is over

“They are tired of [HIV] people not wanting to engage on global health in bigger ways and tired of the exceptionalism. It should overrule everything else. ... it's not that they don't think it's important. It's just that they think that the exceptionalism of structures, funding, focus, and all of that is not sustainable if we are going to achieve UHC goals and SDG goals.” (PCB member)

... There is a new wave of commitment to global health

“There's a lot that we can leverage and a lot that's interconnected. We need to surf the wave of the new sense of urgency and commitment to global health for the benefit HIV. If the HIV world goes defensive and says, "don't bother us, we're the HIV people", that is a recipe for being a backwater. There is a real risk of that happening.” (Donor)

“I also think that we need to work much more on the theme of universal health.” (Key population, women or youth network)

“Is COVID-19 giving us a platform and opportunity to show how as a movement, we can be the global leader? And use this as an opportunity for advancing integration?” (PLHIV network)

... This is the only way the HIV response will be financed

“The move in recent years to integrate HIV into our broader health response, rather than treating it as a vertical response is going to be very important because with declining resources available to countries we need to move towards countries taking ownership of their national responses, being able to be sustainable while at the same time, transitioning from donor funding.” (Key population, women or youth network)

“We recognise certainly that, at least over the next couple of years, the level of resources available to invest in the epidemic is going to decline both at a global level, as well as national level. It therefore means that we have to have a political way to integrate HIV within our public health responses in a significant way so that we don't need that extensive pot of resources for a vertical programme.” (Key population, women or youth network)

“I worry that HIV is increasingly left out. HIV can't be alone, we must be at the table with other things ... So we need to be intentional about having HIV there - but it can no longer be exceptional at being at the table. The only child now needs to be part of this bigger family, and happy in the bigger family - or you might be the spoilt only child that is left out completely.” (Academia and research)

“Even though the price of antiviral therapy has come down so much, there is more and more emphasis on home countries, host countries having to pick up the bill for those services, the only real way to do that is to get away from the vertical freestanding HIV programmes, and begin to integrate HIV into national health.” (Academia and research)

... the strategy needs to be anchored in the broader social, economic and cultural context

“It’s not only about taking an epidemiological reality, but also taking it in its large socio-economic and cultural context. This is what the next strategy should be about, especially for countries with a high concentration of key populations. If we don’t sufficiently consider key populations, and consider the larger context of these people in each country, the strategy will not be sufficiently adapted.” (PCB member)

“It’s an opportunity for the HIV/ Aids movement –which includes not just civil society but also the UN system - to say: We have learned these critical lessons. What is happening now affirms what we have learned. These are the big questions now: That would position the strategy for relevance. And to frame HIV / Aids as part of the larger picture.” (Civil society organisation)

“I do think that the only thing that we can do right now is instead of refusing that narrative around integrated health systems, we lead it. We jump in and lead it, because there is an opportunity here of saying ‘Ja, let’s move beyond single disease strategy, but at the same time refocus that into certain population focus.’” (PLHIV network)

2. The strategy should focus more broadly on co-infections because...

... many diseases like TB, diabetes and cancer are the largest killers of PLHIV

“Given that TB is the largest killer of people with HIV that’s UNAIDS should be playing a larger role about TB.” (Multilateral/ Intergovernmental organisation)

“Co-infection is a big issue here. In our (post-soviet) countries, the first cause of death among HIV+ people is TB. We’ve learned that there needs to be continuity of HIV treatment in TB settings. We also need to increase the involvement of HIV peers and leaders to educate HIV+ people about TB prevention and treatment.” (PCB member)

“UNAIDS should no longer be exclusively HIV/Aids focused. It could help countries to address TB and other diseases common to PLHIV.” (Academia and research)

“What I would like to see is, when there are these broad objectives and strategic directions of the strategy, to also be reflective on what it means for a co-infection.” (Multilateral/ Intergovernmental organisation)

“We have to start thinking outside of deaths caused by AIDS only. They are still there, they’re still significant, but right now people living in HIV are dying of other diseases, non-communicable diseases, cancer diabetes and so and so forth. When we start to think of

indicators we have to start to enter into the realm of other disease areas because that is where deaths are happening.” (National coordination mechanism)

... we should find complementary approaches that do not compete with one another

“We come back again to this one health issue, you know, what is good for one is good for the other. It's not that we should fight these diseases one against the other but this complimentary comprehensive approach.” (Multilateral/ Intergovernmental organisation)

... it increases the international visibility of other diseases

“Integrate other infectious and chronic disease programmes into the AIDS programmes to leverage the quality and results of the AIDS programmes to benefit other diseases such as hepatitis, syphilis and leprosy.” (PCB member)

3. The strategy should focus on AIDS because...

... the HIV response is getting distracted by issues that are not primarily HIV related

“This is a real moment for UNAIDS. They are in financial crisis. There is serious concern coming very much out of UNAIDS itself, where morale is terrible, that the strategy and leadership of UNAIDS isn't going to be about HIV and AIDS, but it's going to be about other issues: structural issues, societal issues, equity issues, rights issues, all of which are hugely important. But is it the strategy of UNAIDS to take on societal dysfunction? Or is it the strategy and the purpose of UNAIDS to articulate and lead and create the conditions for a successful response to HIV and AIDS still with the 2030 target in mind? ... it does feel like UNAIDS is moving off into a direction where it isn't primarily about HIV. It's primarily about those other issues.” (Civil society organisation)

“The concern in the last six months is that UNAIDS and its leadership is sounding less like they're talking about UNAIDS and talking about larger structural and societal issues. The danger is if there isn't that voice around AIDS.” (Civil society organisation)

... UNAIDS should not dilute its core focus

“I've noticed that UNAIDS in this moment hardly talk about AIDS; it's all about health care and equity, and it's not that I disagree with it but it's just that it's trying to play the role of the WHO and it's not a competition that they can win. The 'AIDS' in 'UNAIDS' stands for 'AIDS'. We need to make sure that the primary purpose of the organisation is to fight for AIDS.” (Academia and research)

“In the end rather have a narrower strategy of the things that can make a difference than UNAIDS is trying to put its stamp into everything.” (Individual expert)

... HIV still needs an exceptional response

“I’m still pleading for a lot of exceptionalism for HIV AIDS. The figures are not that good and there are still new cases coming in. We cannot let go of the focused approach.” (Private sector)

How much should the HIV strategy integrate with the COVID response?

“Stay in your lane as I’d like to refer it. The HIV problem is not sorted out... As you do active case-finding for COVID-19, particularly in Africa, there are opportunities where the two can be integrated and work together... But I think the core business of UNAIDS has to be focused on its HIV mandate and that it becomes even more important to fulfil that mandate and do a bit of a catch up of where we’re falling behind.” (Academia and research)

“How do we keep that balance between focusing on COVID and doing the right thing but also not letting or foot off the pedal in relation to HIV?” (Donor)

“Maybe the opportunity is to use the fight against COVID to reenergise the fights against the three diseases in a way that says: ‘if we’re going to fight these, it’s not enough to fight them in the rich parts of the world. We should do it everywhere.’ If we can do this for COVID, we can do this for HIV.” (Donor)

3. Is UNAIDS fit for purpose?

Overview

People have different opinions about whether UNAIDS is fit for purpose to continue to lead the HIV response, especially in the context of other pressing challenges and pressures

“Even before COVID-19, there were people questioning the need for UNAIDS. If I was the ED, I would be very worried. What is UNAIDS’ raison d’être? I must say in recent years, it seems to have lost its shine.” (Academia and research)

“UNAIDS is at a precipice. If it doesn’t get this thing right, it will die. UN agencies don’t entirely disappear but they lose their relevance. The danger is that the epidemic is raging unchecked. The perception that AIDS has been conquered will accompany the disappearance of UNAIDS. That’s my biggest worry.” (Academia and research)

“UNAIDS needs to be fit for purpose because you are advancing your case against a much more pressing challenge [Covid].” (Individual expert)

There is some debate about whether UNAIDS should be absorbed into other agencies, in particular WHO

“Can the work of others in UNAIDS be integrated with WHO at the country level? I’ve been more focused on local issues in recent years and from that outside perspective, I think WHO has played a much more practical role given the phase of where we are with the epidemic.” (Academia and research)

“So you hear more about WHO and Global Fund. Why do we need three organisations doing similar things?” (Academia and research)

“My fear is that UNAIDS will be absorbed by the WHO. This would be a huge mistake, especially for us, the community sector.” (PLHIV network)

“The formation of UNAIDS as a joint programme were the failure of WHO to address HIV – let me put that on the record because that is very important. Because those who are arguing to disband UNAIDS in the next five years are going to give it back to WHO, who will screw it up again.” (PCB member)

Many feel that UNAIDS is or used to be an important and effective partner.

“UNAIDS is an important partner to people living with HIV. UNAIDS has always been a champion. I have a real commitment to UNAIDS, wanting to see it work.” (Donor)

“UNAIDS is a powerful institution in its ability to get coalescing around the world.” (National coordination mechanism)

But some have lost faith in it or feel that it is no longer relevant.

“There has been a period of time where a lot of people have lost a lot of faith in UNAIDS - not in the people but in terms of its direction. The energy and expertise that resides in individuals is not being harnessed and directed in the right ways. I am really excited that this process is happening and I am hoping for a strong outcome because without a strong UNAIDS its going to be a hell of a lot harder to make the progress that we need to make.” (Donor)

UNAIDS has forgotten that it is a unique vehicle within the UN system and has become unnecessarily mired in the bureaucracy of the United Nations.

“UNAIDS is a bit unique.... it is this Joint Programme and a means through which to coordinate and integrate the UN around a common set of challenges.” (Multilateral/ Intergovernmental)

“What UNAIDS has done, I think quite smartly, is to say that it's not an entity. It is not an agency. It is a Joint Programme. And I think that one of the things that it has lost in recent years has been a focus on that reality.” (Academia and research)

“Programmes started becoming more bureaucratic, and by 2016 we could see the gains that had been made over 10 years were being nullified. Regression has continued since then.”

“The UN tends to be tied up by bureaucracy and autocracy and its own politics and so on and so forth. But from the word go, UNAIDS was allowed to do that and it should retain that it should protect it jealously because it can amplify other people's voices and it can ride with other people's voices to demand change.” (Individual expert)

“There's something fundamentally wrong with how UNAIDS works – it is too bureaucratic, lazy, self-serving with a patriarchal culture. Very frustrating to engage with.” (Civil society organisation)

“The strength of UNAIDS in the past was that it was more like an NGO than a UNAIDS bureaucracy. I don't know how it is at the moment.” (Individual expert)

Over the past few years it has become beset with internal issues

“Where UNAIDS kind of lost its mojo, was in a lot of inward looking issues. ... there were sex scandals and drama inside the organisation that destabilised it, and turf wars within the organisation, and wars between the co-sponsors and the UNAIDS secretariat. All of that meant that the organisation flipped inward very much more than it should have. And it started thinking about its power base and its mission and jealously guarding its control over certain things in ways that really undermined the point of it in the first place. Which was not to set up an agency that would tackle AIDS so that everybody else could ignore AIDS, but instead to create a Joint Programme that mobilised the entire UN system.” (Academia and research)

This had an impact on morale and staffing

“Winnie has inherited a pretty dysfunctional organisation, where people are not happy, the levels of favouritism and factions that were created... the technical position somewhat starved and ten people being in positions they probably shouldn't be. Expertise in community responses and mobilisation have been eroded.” (Donor)

“There were specific jobs with competencies that people were hired against - social mobilisation and partnerships - hired to do role - as UNAIDS moved into this system of mobility and rotation, anybody got put into those positions - increasingly - got people that really didn't have the right skills in positions - a lot got dumbed down.” (Donor)

“You look at some of the regional directors and you think ‘how did these people get there?’... I don't think a lot of those people have enough other experience. Too many are just UN bureaucrats and not living in the real world.” (Individual expert)

The structure and governance of UNAIDS as a Joint Programme is a challenge

“Co-sponsors are very variable in their commitment to a rights agenda.” (Donor)

“Nobody cares about HIV except UNAIDS. Now I know that UNFPA, UNICEF and others have their global strategies on HIV response, but I would like to be mistaken or misinformed, but at the ground, UNAIDS is the only agency really caring about HIV response in the country.” (PCB member)

“So even though harm reduction has been used in UN documents for the past 20 years, we still had a scenario on an annual basis where UNODC struggles to use the term harm reduction. And this is the agency that's supposed to be representing harm reduction and people who use drugs in the UNAIDS programme.” (Civil society organisation)

“UBRAF has been underfunded dramatically in recent years, and that has led to a lot of the turf wars and a lot of the reduction in participation, and reduction in coordination because many of the agencies are not getting money from UNAIDS and the way that they used to, and therefore don't have staff to support that.” (Academia and research)

Some have concerns about the strength and legitimacy of the UNAIDS Secretariat to effectively coordinate the co-sponsors.

“Over the years, the co-sponsors became disenchanted and began to parallel their own initiatives, largely ignoring UNAIDS.” (Academia and research)

“I don't see enormous collaboration effort, I see the opposite, I see not one UN, but like five.” (PCB member)

“In Geneva at headquarters, ... in 2006/7 the Joint Programme with 11 cosponsors and the UN secretariat, there was a division of labour? And then prevention was something that was distributed amongst three or four agencies.... Today I don't think UNFPA is doing anything for sex workers, UNODC anything for drug users, etc.... And where is the

secretariat? Because the secretariat should have taken the responsibility of coordination.” (Individual expert)

“No longer considered relevant by other UN agencies: Several UN agencies are strategizing now. UNDP is thinking about where it will be in 20 years time. WHO is reinventing itself under intense pressure. I don’t see them asking how to bring UNAIDS in, they’re doing it irrespective of UNAIDS. The co-funders are going ahead with big plans to reconfigure themselves in the modern world and they’re not consulting UNAIDS – which is a sign that you’re isolated.” (Academia and research)

Strategic questions

Are we talking about UNAIDS secretariat or the Joint Programme?

“So this is a tricky question to answer, because the secretariat is one and the joint programme is a different thing. It’s all the same but the joint programme with all the co-sponsors does a lot... it would be interesting to see how other people respond to that question about whether they differentiate – or whether they just automatically think about the secretariat has become a thing unto itself, given that it has nearly 700 staff and lots of field offices and regional, so it is larger than several UN organisations on its own, yet the strategy is for the joint programme, for everyone.” (PCB member)

Is UNAIDS still relevant?

“The normative concerns that pushed the political players to set it [UNAIDS] up at the time have not changed. The idea of the institution is still relevant. Has it come close to achieving it? The purpose of setting it up hasn’t gone anywhere.” (Academia and research)

“So how do we see UNAIDS in the future? What is the role of UNAIDS as part of the UN family in the future? This is important mainly because in the history of health responses, it’s only HIV, where you have a dedicated UN programme gathering all UN agencies and exercising that multilateral collaboration among various UN agencies for the particular disease. It’s never been done before UNAIDS. And it has never been done again in other fields in succeeding... I think UNAIDS remains to be relevant of the time. There’s so much information and learnings that we can learn from the UNAIDS, regardless of how imperfect it is.” (Civil society organisation)

“The role of UNAIDS is even more important in the current environment. UNAIDS continues to be relevant. UNAIDS have convening power, they are a legitimate and independent voice, bringing together multiple actors at the national, state and global stage supporting government to clarify and develop integrated responses which are not vertically determined (by donors or external actors) but that are grounded in the local reality.” (PCB member)

“For me, having a structure like UNAIDS can provide a useful example that can be learned from. We can learn from their flexibility and from how it collaborates with community

organisations and what results from that collaboration. We should document what is done. By doing so, it could teach us even more.” (PLHIV network)

“UNAIDS has a critical role to keep emphasising that we can’t solve the epidemic through clinical care and Ministries of health. You need community care partnerships that go beyond the scope of Ministries of Health and include, for example, Ministries of Justice and Reform.” (Individual expert)

“In the past years, we saw a lot of competition, not among the institution, but among people who were following the agenda between Global Fund and UNAIDS, as UNAIDS was not necessary anymore. And people start just thinking and focusing the Global Fund, which is absurd because UNAIDS is providing data, it's doing research, is providing the guidelines is, who is intellectually speaking, driving the response.” (Civil society organisation)

“I feel strongly UNAIDS still has role. I think it would be a disaster if UNAIDS would be broken up into pieces, because you need consistent high level platform to articulate, argue, fight for the response to HIV and AIDS. And if it breaks up UNAIDS into a bunch of component parts, then I know that it will be a major setback.” (Civil society organisation)

“UNAIDS has been mostly about advocacy in recent years. Do we still need a huge organisation to do that or can it be absorbed by the other agencies?” (Academia and research)

“We need to be very careful and as UNAIDS, this is not its time of strength. It's taken quite a knock in the past two years from all the issues around sexual harassment, having a new executive director coming in, the challenge of the goals, 2020 targets not being met.” (Academia and research)

“Unless UNAIDS can articulate an identity that is clear and differentiates itself from other players, then the constraint will be loss of funding, a less powerful voice, a less relevant role. That needs a lot of attention in the ten-year strategy. That work needs multiple voices, internal and external. But underscoring this idea of multiple determinants of vulnerability and ensuring access to prevention, care and treatment is at the heart of it. Recognising that this beyond epi-statistics and bio-medical responses. Saying that we ground our work in a human rights vision that leads to greater information and prevention and care, etc.” (Individual expert)

“One of the ways it can be strategic is to harvest and share the lessons from HIV that ought to inform and help us understand COVID 19 - Documenting and sharing the lessons from HIV for the COVID response - highly strategic role for UNAIDS - partly pragmatic and cynical and shoring up UNAIDS' relevance but its also a really important contribution to global health.” (UN Agency)

“UNAIDS is preoccupied with advocacy and new fads of advocacy. But that’s not about driving governmental on-the-ground changes for the better, but showing that the institution is relevant.” (Academia and research)

“Why is UNAIDS concerned about Covid-19? If it did its job well, it would leave Covid-19 to someone else. They’re looking for a political anchor of relevance. We need to prevent them from doing that.” (Academia and research)

Is UNAIDS willing and able to transform itself?

UNAIDS needs to do a lot of soul-searching

*“UNAIDS need to look at its internal governance structures very, very seriously”
(Individual expert)*

“If we want change to happen we need to start with the UN agencies themselves. If they know that the systems are wrong, they need to be changing the systems.” (PLHIV network)

“There needs to be a lot of soul searching and honest questioning of its effectiveness, at both the country and global level. In some countries, it has done very well but maybe not in others.” (Academia and research)

“As organisations we have a responsibility to become much more like the society we want to create. We need to transform ourselves as organisations. Both my organisation and UNAIDS have important work to do on that front. If not, we lose much of our legitimacy. That has to do with dealing with conditions that have created pockets of power abuse. The future strategy should visibly reflect the acknowledgement to transform ourselves. This isn't something that happens quietly in the background, or silently. This kind of organisational transformation must be part of the strategy.” (Civil society organisation)

“There has been a change in leadership that has been welcomed. There is still a way to go for UNAIDS to gain trust. A number of countries have threatened to reduce and pull funding, perceptions of issues internally. UNAIDS has to be transparent and public in dealing with those issues.” (Civil society organisation)

It needs to address the unnecessary bureaucracy and inefficiencies that have crept in.

“There will need to be quite significant shake up in terms of the structure and how it is organised to deliver, and I think it would also need co-sponsors to be responsive and bought in as well.” (Donor)

“They’ve got to find some of the ways of dismantling the bureaucracy.” (Individual expert)

“We need all of those UN Agencies, but without question they are not efficient. There’s variable quality of staff. They’re expensive organisations to run... UNAIDS... there’s still a lot of dead wood around. It has to, in order to be attractive, and relevant, and do good work, they have to make sure that its systems are efficient, that they people that they employ are the best that you can get.” (Individual expert)

“The way they appoint people at country level needs to be rethought. They are an obstacle to progress at a country level. A lot of people are coming from the government – former

ministers of health become senior people in UNAIDS and WHO. Over time, that means that people with the guts and people from civil society can lose.” (Civil society organisation)

“It does not require UNAIDS to have in house capacity on everything ... but it does require that their staff be functioning at a very high level and have both the scientific skills and the diplomacy skills to be able to navigate that world of being able to harness others effectively.” (Academia and research)

It needs to address its internal culture

“There’s a culture issue in the organisation. Lack of agency and speaking out in the structures below the ED, which translates into country offices. You need leadership support for those people. Feminist leadership principles. There’s a very weird culture that no-one can speak on behalf of the organisation. It’s very hierarchical. Everything needs to be checked before anyone can move. That doesn’t make you brave and agile. UNAIDS used to act very differently.” (Civil society organisation)

“Very personally, I feel that the patriarchal culture ripped the organisation. Hopefully, if Winnie gets enough space and time to address it.” (Civil society organisation)

“Internally, what does the organisation think? What is the culture? How committed are people? Are they buying into the strategy? Is management fair? All these things are often difficult but are key. If the people who work in it don’t believe in it, you don’t reach your goal.” (Academia and research)

How can the UNAIDS Secretariat strengthen its relationship with co-sponsors?

“Politically I would ensure that the coalition that makes up the Joint Programme is strong.” (Academia and research)

“It [the next strategy] is clear on UNAIDS as a secretariat’s role, UNAIDS co-sponsors’ role, so they don’t get bogged down in turf battles over division of labour and the usual crap. But also it’s role vis-à-vis the other global health architecture, it’s role vis-à-vis countries, and I think the clearer it is on that, then the clearer and easier it will be to then create a structure within the UNAIDS secretariat that serves the delivery of that strategy.” (Donor)

“To make sense in the future, UNAIDS has to behave as a co-sponsor. It needs to piggyback much more with what the other agencies bring.” (Civil society organisation)

“They need to return to a genuine commitment to working with others and not necessarily always trying to be the preeminent voice. They have to look deep inside as to whether they’re prepared to be a truly collaborative effort and additive effort... The amount of junk between the agencies and so on is a lot of wasted energy and, and time.” (Civil society organisation)

“I think one of the core pieces that this strategy needs to think through a little bit is how post 2021 does the UNAIDS reach a new level of collaboration and recapture the energy of

bringing together all the UN agencies, relying on them in order to move the ball because UNAIDS is in and of itself can never do that.” (Academia and research)

Can UNAIDS strengthen its relationship with other key partners, especially the Global Fund?

“On co-ordination between UNAIDS and Global Fund, PEPFAR and other co-sponsors. In certain periods, this is good and other times it’s not very collaborative. I would like to see a stronger link so that there is more concerted effort in the same direction.” (Civil society organisation)

“Pay attention to co-ordination. Think about UNAIDS and the Global Fund and how much duplication there is and how they don’t talk to one another, how much work is happening at cross-purposes and how much wastage there is, with everyone flying around.” (Civil society organisation)

Global Fund is a funding mechanism. They have all the money and UNAIDS has no money. Is there a way to striking a deal that could strengthen UNAIDS and at the same time strengthen the Global Fund so that ultimately it benefits people and countries?” (Academia and research)

“The Global Fund is also going into strategy development. I keep asking: is there some kind of coherence / synergy here? It seems silly not to do this together, so that there’s understanding of what the Global Fund will do and what UNAIDS will do ... It would be a waste if two global AIDS agencies don’t collaborate on their strategies.” (Civil society organisation)

“One would hope that the Global Fund and UNAIDS strategy have some very common language on some key things common things, targets, etc.” (Donor)

Should the next strategy develop a 9th Result area, around governance of the Joint Programme?

“I would definitely add a ninth one [Result Area] and that is governance. Governance of the Joint Programme. I think it needs to happen. I read the document, it is very low in priority, somewhere a couple of paragraphs, but I think if we really want to be fit for purpose this would be area no. 9, as internal governance of the Joint UNAIDS programme and how we are going to have a paradigm shift in that – not just window dressing here and there. A total shift in paradigm as to how UNAIDS is working at the country and global level. If you don’t do that you are missing an opportunity for the next five years, and all those key result areas, and the other 8 of them, if this one is not done you are not going to achieve any of them – and I can very safely say that.” (Individual expert)



A few concluding reflections

This section concludes the report with a few emerging reflections from Reos Partners. These build in large part on the consolidated strategic questions of the previous sections (See Appendix D for a consolidated list of all questions), as well as reflections of feedback from the UNAIDS editing team on previous versions of this document.

Key strategic conversations

Reflecting on the consolidated list of strategic questions (Appendix D) a number of areas for dialogue surface. These include, but are not limited to:

- Addressing stigma and discrimination in a real and meaningful way
- Collaboratively engaging around issues of data, evidence and target setting
- Sustainable financing
- Leveraging the COVID moment: threats and opportunities
- Questions relating specifically to the governance of UNAIDS – both the Joint Programme and the Secretariat,

Appendix D provides a useful resource as a starting point for any of these conversations.

There is lack of clarity around the terminology, language and framing used by different actors

As mentioned in the introduction, there is lack of clarity around how different respondents define different terms, and therefore uncertainly what a particular respondents means when they use some terminology. Some examples are included below.

- When people are talking about UNAIDS are they talking about the Secretariat or about the UNAIDS Joint Programme as a whole?
- When they refer to the “strategy”, are the referring to the UNAIDS strategy or the Global Aids Strategy? And drilling in deeper, when they speak about the UNAIDS strategy, are they speaking about the or the internally focused UNAIDS strategy/implementation plan.
- Words such as integration and collaboration have different meanings for different people.
- Many speak about ending AIDS, but this is not the goal
- References to targets

In order to make progress together, the participants of the workshops and strategy development process will need to spend time developing a shared understanding around terminology and definitions.

The gap between rhetoric and transformative action

It seems that on the whole, the global HIV response is relatively clear about what **should** happen and what **needs** to happen, but is not clear about how to actually effect change, or what would be required to get from current reality to the desired outcome. This is particularly true for the significant social and structural barriers that the AIDS response says it needs to address, such as addressing stigma and discrimination and the structural drivers of inequality. Similarly, there seems to be a gap between the aspirations around, for example, community-centredness, needing to develop granular approaches and collaboration, and effectively actioning these aspirations. Thus, much of the strategy development process is likely going to need to engage



in conversations around what such transformation would demand, at individual, institutional, sectorial and multi-sectorial levels. For example, what changes in mind-sets might be required? What would be required to turn into, rather than away, from difficult, uncomfortable conversations? What responses might be required when change is not possible? How might different actors mobilise their agency in new and innovative ways?

What next with this report?

As mentioned in the introduction, the primary purpose of this advanced draft report is to provide a shared starting point for the conversations that will be undertaken during the workshop occurring on the 20th and 21st August 2020. The report will then be finalised for the Multi-stakeholder Consultation on the 16th September.

APPENDICES

A. List of interviewees

Interviewee(s)	Interviewee organisation
Adeeba Kamarulzaman	University of Malaya
Alejandra Oraa	CNN
Alex Coutinho	Expert Individual
Allan Maleche	Kelin
Allesandra Nilo	GESTOS
Alvaro Bermejo	International Planned Parenthood Association
Andrew Kambugu	Institute for infectious diseases, Uganda
Assumpta Reginald	ICW Nigeria
Cédric Nininahazwe	Y+
Chip Lyons	Elizabeth Glaser Paediatric AIDS Foundation
Chris Beyrer	John Hopkins Bloomberg
Chris Stokes	UN DCO
Christine Stegling	Executive Director of Frontline AIDS
David Barstowe	Faith and HIV next Decade
Enos Okumu Masini, Lucica Ditiu, and Wayne Van Gemert	Stop TB
Erika Castellanos	Transactivists and Global Fund
Gennady Roschiupkin	ECOM/EECA
Gerson Pereira, Marcelo Freitas, Juliana Machado Givisiez	Ministry of Health, Brazil, Director of national AIDS and STI Programme
Helen McDowell	Viiv Healthcare
Htun Nyunt Oo	National Aids Programme, Myanmar
Ivan Cruickshank	Caribbean Vulnerable Communities
Jeanne Gapiya-Niyonzima	L'Association Nationale de Soutien aux Séropositifs et malades du sida (ANSS)
Jeffry Acaba	APCASO
Jeremiah Johnson	Treatment Action Group
Joe Amon	Drexel Dornsife School of Public Health
Jonathan Cohen	Open Society Foundations
Jonathan Gunthorp	SRHR Africa Trust
Jose Samaniego	UNHCR
Judy Chang	INPUD
Julia Martin	United States Government: Department of State
Jullian Kerbogossian	GNP+
Karina Bravo Niera	Platform of Persons Who Perform Sex Work (PLAPERTS)

Interviewee(s)	Interviewee organisation
Kate Thomson	Global Fund
Kevin Osborne	International AIDS society
Lady Roslyn Morauta	The Global Fund to Fight AIDS, Tuberculosis and Malaria
Lillian Mworeko	ICW
Linda-Gail Bekker	Desmond Tutu HIV Foundation
Marc Angel	Member of the European Parliament
Mark Blecher	National Treasury
Martha Tholanah	Africa Think Tank, (consulting for Amplify change fund from interview)
Matthew Kavanagh	Georgetown University
Michael Kirby	Former Justice of the High Court of Australia
Nana Poku	University of KwaZulu Natal (UKZN) and HEARD
Nafsiah Mboi	Independent
Naomi Burke-Shyna and Olga Szubert	Harm Reduction International
Natalia Kanem	UNFPA
Nduku Kilonzo	NAC Kenya
Olga Varetska	Alliance for Public Health
Peter Piot	London School of Hygiene and Tropical Medicine
Peter Sands	The Global Fund to Fight AIDS, Tuberculosis and Malaria
Praphan Phanuphak	Red Cross Thailand
Prasada Rao	Previous Special Advisor to UNAIDS
Quarraisha Abdool Karim	CAPRISA
Rico Gustav	GNP+
Ruth Morgan Thomas	NSWP
Sani Aliyu	Nigerian Government
Sha'ari Ngadiman and Anita Bt Suleiman	Malaysian Department of Health
Sipho Mthathi	Oxfam South Africa
Smail Mesbah	Ministry of Health Algeria
Stefaan Van der Borgh	Recently retired from Anglo American
Suwit Wibulpolrasert	Ministry of Health in Thailand
Svetlana Doltu	Act for Involvement (AFI)
Wafaa El-Sadr	Columbia Mailman School of Public Health
Yana Panfilova	Teenergizer
Yury Ambrazevich	Government of Belarus

B. Guiding questions for the interviews

Opening

1. I would like to start by learning a bit about your background. Could you tell me something about your personal history, not your CV, but your story, especially as it relates to HIV/AIDs?

Learning from the past

2. We are seeing different levels of progress in different countries, the different population groups including children, adolescents and key populations for example and priority areas with regards to reducing new HIV infections, reducing AIDS-related deaths and eliminating discrimination. Based on your perspective and experiences, why do you think we are seeing this different levels of progress? What is happening in your particular context?
3. What pivotal events/or game changers can you identify in the past in relation to the HIV/AIDs response that provide important lessons for the future?
4. The three goals of the current Global AIDS strategy developed by UNAIDS are by 2030: 1) to eliminate new HIV infections; 2) to eliminate AIDS-related deaths and 3) to eliminate discrimination. How do you think UNAIDS can be most helpful in achieving the goals that are set.

What we need to be paying attention to now and into the future

5. I would like to understand your main concerns and uncertainties related to the HIV/AIDs: If I were a clairvoyant and you could ask me three questions about the future, what would you ask?
 - a. Now if you were the clairvoyant and the future was a “good” one, how would you answer these same three questions? What would have happened?
 - b. If the future was a “bad” one, how would you answer these three questions?
6. What do we need to be paying attention to as we develop next global AIDS strategy?
7. When we look at emerging and/or continuing global health issues (the current COVID pandemic being just one example), what lessons can the HIV response offer the world (both it’s successes and shortcomings)?
8. And what can the HIV response learn from the response to COVID 19? What are the impacts and risks of COVID-19 response to the gains made in the HIV response towards achieving the 2030 targets? Can these set-backs be made up in the remaining time?
9. What major constraints do you perceive that limit what can be achieved with respect to reaching the target of end of AIDS as a public health threat by 2030?

Epilogue

10. When you move on from your current position, to another position, or to retirement, what do you hope to leave behind that will be associated with your period in this job: what do you want to be remembered for?

Feedback on the process

11. What are your hopes for this strategy review process? And what are your fears?

Closing

12. Anything to add?
13. Any questions for me?

C. UNAIDS strategy process Phase one strategic design questions

Main strategic design question:

What will it take to end the AIDS epidemic as a public health threat by 2030?

Strategic design sub-questions

14. What worked well, where and why?
15. What worked less well, where and why?
16. What are the most important barriers/ constraints to ending the AIDS epidemic, and why?
17. How might these barriers/ constraints be addressed/ overcome?
18. What are the most important enablers to ending the AIDS epidemic and why?
19. What should we continue, stop and start doing that is new and / or innovative?
20. What impact may COVID have on ending the AIDS epidemic and why?
21. What can we learn from the past, including from the COVID pandemic?
22. What can others (outside the AIDS ecosystem) learn from the HIV response that in turn could have a bearing on ending the AIDS epidemic?
23. What factors in the world may have a significant impact on the achievement of the above goals?
24. What focal questions/principles need to guide the update of the new strategy?
25. What option, as outlined to the PCB, might be most appropriate for the next strategy and why?

D. Consolidated strategic questions

The strategic questions from Sections 3 to 5 have been consolidated under a series of themes, below, for easy reference.

Language, understanding and agreement

1. Do we adequately understand why prevention is failing in each context?
2. Do we have a common understanding of the language we are using when it come to goals, visions and targets?
3. Are we talking about UNAIDS secretariat or the Joint Programme?

The AIDS response in context

1. How to put AIDS back on the agenda in a time of competing demands and interests?
2. How does the AIDS community continue to hold space for HIV while also contributing to the global health response?
3. What should be the focus of the next strategy?
4. How to leverage the experiences from the HIV response to build preparedness for future pandemics?
5. How to improve treatment adherence and avoid drop-outs especially amongst vulnerable populations, under disruptive conditions?
6. How to integrate human rights with regards PLHIV, vulnerable groups and key populations into the health system?

Addressing inequalities

1. How to ensure that the prevention responses address the root social drivers of new infections?
2. How can secondary education, including sexuality education be strengthened?
3. How to meaningfully deal with the structural drivers of inequality?

Stigma and discrimination

1. How to adequately elevate the importance HIV prevention into the public arena, especially in political and social contexts where open references to sexual and reproductive rights and health and sexuality remain taboo?
2. How to adequately prioritise and fund different aspects of prevention, especially the more contested aspects like sexuality education and harm reduction?
3. How to reduce or address discrimination in a world that believes key populations and PLHIV should be shunned or are not deserving of support?
4. What can communities themselves do to reduce stigma and discrimination?

People, communities and civil society

1. How to ensure that PLHIV and communities are genuine partners in this strategy process?
2. How to value and credit the work of the community sector?
3. How to adequately strengthen community organisations?
4. Can we really reach the last ten percent?

Collaboration

1. How do social movements build solidarity?
2. How to strengthen collaboration between communities and the public sector?

Inclusion of particular actors

1. What is the role of private sector in the HIV response?
2. What is the role of faith-based organisations in the HIV response?

Power and politics

1. What are the difficult conversations that need to occur in relation developing a granular response?
2. How do we deal with power dynamics between national government and local actors (including local and community actors)?
3. How to strengthen national country leadership in the context of competing priorities and national interests?

Who to focus on

1. How does the next strategy balance the focus on key populations with other underserved populations?

Mind-set challenges

1. How to address the shift in mind-set required to move from a top-down to a bottom-up approach?
2. How to change mind-sets around medical professionals as “experts” of the HIV response?

Data and evidence: indicators, targets, measurement

1. What is the role of evidence in the human rights response to HIV?
2. What should the goals, visions and targets for the next strategy be?
3. How to ensure the targets are meaningful and appropriate for communities?
4. How to ensure that the data being used in decision-making and measurement is reliable, up to date and accurate?
5. How to adequately measure stigma and discrimination?
6. How to adequately measure community-delivered services?
7. How to ensure responses are based on granular, context-specific assessments?
8. How do we make sure that the criteria we use to resource particular communities, countries or regions are adequate?
9. How to ensure accountability and impact?

Biomedical questions

1. (When) will we find a vaccine?
2. (When) will we find a cure?

Financial questions

1. How do you make an investment case for prevention?
2. How to make treatment more affordable and accessible by more people?
3. How to strengthen the global HIV response in the context of shrinking global financial resources and the long-term economic impacts of COVID?
4. How to counter the politics of funding?
5. How to rethink who gets funding especially as it relates to Middle Income Countries?
6. How to make a compelling investment case? And what to prioritise?
7. How to ensure transparency regarding where the money is being spent?

Communications

1. What should the communications strategy be?

Leveraging the COVID moment

1. How to leverage opportunities or innovations from the COVID-19 crisis?
2. How to use COVID-19 to build a more robust and flexible strategy?
3. How to use the COVID moment to transform health systems?
4. How to use the COVID moment to promote the role of community-led responses and organisations in health systems strengthening?
5. How much should the strategy align with COVID (financially)?
6. How much should the HIV strategy integrate with the COVID response?

UNAIDS

1. What is UNAIDS' role in this dual (biomedical and human rights) response?
2. What is the role of UNAIDS in supporting and engaging communities?
3. How does UNAIDS support this granular and localised approach?
4. What leadership role does UNAIDS need to take?
5. Is UNAIDS still relevant?
6. Is UNAIDS willing and able to transform itself?
7. How can the UNAIDS Secretariat strengthen its relationship with co-sponsors?
8. Can UNAIDS strengthen its relationship with other key partners, especially the Global Fund?
9. Should the next strategy develop a 9th Result area, around governance of the Joint Programme?
10. What kind of leadership is needed from the UNAIDS executive director?
11. What is the role of UNAIDS in supporting and engaging communities?